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INCLUSION OF PERSONS WITH DISABILITIES. POLICIES, PRACTICES, RESEARCH AND NARRATIVES
INCLUSÃO DAS PESSOAS COM DEFICIÊNCIA. POLÍTICAS, PRÁTICAS, INVESTIGAÇÃO E NARRATIVAS

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In publishing this issue under the title "Inclusion of Persons With Disabilities. Policies, Practices, Research and Narratives", the *Lusophone Journal of Cultural Studies* (LJCS) becomes, indeed, the first Portuguese journal on social sciences to dedicate one of its issues exclusively to the inclusion of persons with disabilities (PWD). Thus, it is an important milestone as it contributes to constructing a fairer and more inclusive society for PWD. If nothing else justified the timeliness of this publication, it would be enough to remember that historically accumulated knowledge shows beyond doubt how and how much PWD have been socially discriminated against, rejected and despised. For this issue's edition, it is worth mentioning that the Communication and Society Research Centre's directors and editors were inspired by Articles 8 and 27 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD; Convenção Sobre os Direitos das Pessoas com Deficiência, 2006). The particular purpose of this issue is to contribute to a better social awareness of disability, help combat stereotypes and prejudices, and promote the rights of PWD. The rights of PWD, which, since 2006, following the promulgation of the convention by the United Nations, have officially become a human rights issue — the right to respect, dignity, choice, freedom, work, schooling, starting a family, among others.

When we discuss the need to promote the inclusion of PWD, we can refer to Arnold Van Gennep (1981), to his concept of the rites of passage to analyse how the processes of inclusion of PWD tend to occur in the different social spaces, work, education or leisure. These spaces, where several contradictions, paradoxes and dualisms show that losing the status of socially excluded persons based on disabilities, does not necessarily lead to gaining the full status of socially included persons. That means effective inclusion is still to be achieved. People remain in the so-called "liminal status", in a state of social suspension, in a limbo of vagueness and ambiguity, perpetually placed between inclusion and exclusion, as Robert Murphy, Alain Blanc, Michel Calvez and Charles Gardou, and others have argued. As such, the production of scientific knowledge is fundamental

to understanding the factors that interact in social spaces where inclusion meets exclusion. In essence, these factors stem from socially established beliefs that place PWD at the margins of the production of so-called proper social relations. Such factors drive the expression of cultural antagonisms between disability and "normality", equally prevalent in the arguments stakeholders use about the presence and participation of PWD in those spaces. In the liminal status, people are hidden from the remaining members of society, in what Victor Turner (1990) calls "structural invisibility", so they are easily disposable. In an ambiguous situation, persons with disabilities are the target of exclusionary social attitudes and practices, as their liminal status makes them symbolically invisible. In other words, as Ravaud and Stiker (2000) state, they are "neither truly alive, nor truly dead, nor truly excluded, nor truly included" (p. 2). In short, they are in transit between exclusion and inclusion because hypothetically, they may either return to the previous state of exclusion or be effectively included.

Hence, social research on disability can contribute to the inclusion of PWD and to improving their quality of life for multiple reasons. As such, it should be disseminated to communicate theories and findings of interest to academics, regulators, journalists, activists, policymakers, professionals in organisations of and for PWD, including PWD themselves. That is the strategic approach of this issue of LJCS. It is intended to promote the dissemination of scientific knowledge against the backdrop of challenges related to disability. Ultimately, it is about contributing to abide by the principles of the CRPD towards a more inclusive society, respectful of human rights. This dissemination strategy involves reaching out to stakeholders engaged with disabilities, individuals, families, (re)habilitation organisations and their professionals, including PWD, to raise social awareness of the challenges affecting them and the solutions to eliminate or mitigate those challenges. Furthermore, it aims at increasing awareness of the rights of PWD, as determined in Article 31 of the CRPD. It expressly urges the creation of scientific knowledge in this field. It should also contribute to the success of the millennium development goals, strongly linked to meeting the needs of PWD. The eight articles included in this issue serve these purposes outstandingly well.

Although more diffuse and comprehensive, it is essential to highlight the importance of scientific knowledge in driving social change. All we need to do is observe the problems posed by population ageing (leading to an increasing number of impaired persons) and acquired disabilities stemming from social organisation risks, impacting the healthcare systems and the functional and bio-psychosocial rehabilitation processes. So to research in disability and to disseminate research results is to contribute towards the improvement of (re)habilitation policies and practices, assuming that, according to Robert Shalock and Miguel Verdugo's research, the promotion of quality of life for PWD is played out within the context of daily life. These authors are now proposing merging the quality of life and the support models. The purpose goes beyond rehabilitation to improving the quality of life through support from the living environment (family, professionals, organisations, administrations).

Furthermore, since disability is so deeply rooted in social systems, there is a myriad of issues requiring scientific research from a cultural and social or multidisciplinary approach. There is plenty of room to develop focused, comparative or longitudinal studies within national, regional or international scope, challenging the consolidation of partnerships of researchers from Portuguese-speaking countries, and Latin American countries and the European Union. We should add that this issue of LJCS focuses on the mobilisation of social researchers, advocating inclusive values towards identifying, understanding and explaining the difficulties and problems experienced by PWD. In addition to their physical, sensory and cognitive limitations, these persons live in social contexts governed by social rules that discriminate, devalue and exclude them. Rules produced and reproduced in the relationship between disability and "normality", that is, in the moments and spaces of interaction between PWD and their physical and relational social surroundings.

Each PWD is a unique being who may experience different causes and consequences of his/her situation, depending on the type and degree of disability and the concrete physical, organisational, and social environment of his/her daily life. That is why it is important that scientific knowledge also helps understand and explain how individual experiences add to the social construction of disability. Exclusion and discrimination of PWD are not just a result of the limitations posed by disability per se or of their class or socio-economic status. Exclusion and discrimination also stem from living and mobilising in environments that do not account for their physical, social, communicational or relational needs (transport, lifts, stairs, service desks, books, sign language, audio recordings...).

Social research must also analyse public social policies that directly or indirectly target PWD. It should do so considering their connection with the practices of organisations that promote inclusion. To understand and explain how they interact in reproducing and/or transforming the quality of life of PWD. These social research needs extend to analysing the processes, practices, discourses and strategies through which public and private agents apply the CRPD principles. The ensuing scientific knowledge is essential for understanding how disability is socially and politically (re)constructed. Thus, by bringing together governmental policies and organisational practices, the place of disability in society is strengthened, and the rights of PWD are acknowledged. Although we are going through a historical moment with a notorious slowing down of organised civic and citizen action, the social movements for disability, particularly in Portugal and Brazil, were determinant for creating, adapting and transforming almost all existing specialised organisations. Particularly in obtaining resources, developing the legal framework, and improving the physical or socially built environment. These movements' actions require extensive study in their multiple relationships with the State and society, their strategies and practices for action. Furthermore, as disability exists everywhere and in all

known cultures, it is essential to find answers to questions: is there a culture of disability emanating from the various categories of PWD and disability in general or not? In other words, is there a culture of blindness or not? What about hearing or mobility impairments? Are they true cultures? Or are they just subcultures or counter-cultures? That sets the stage for investigating how definitions, treatments and life experiences of PWD are formed and vary according to the different cultures or subcultures within a given society or social environment.

The knowledge of social sciences is also fundamental for understanding physical and social barriers, why they persist and promoting a better redistribution of public resources for eliminating them. It is equally vital to promote rigorous and permanent knowledge on the qualitative and quantitative composition of the population with disabilities, on the impacts of new forms of defining disability, and on their measurement and implementation. In this regard, research is required to create valid and reliable measuring instruments and help solve the many problems inherent in data collection. Moreover, social research should be interested in studying the physical and social environments surrounding the lives of PWD. These are essential research to understand the different factors of the social construction of disability (e.g., the consequences of physical and environmental barriers, attitudes and dominant social representations, risk factors associated with urban and rural lifestyles and their prevention). As we know, such factors limit opportunities for the inclusion of PWD in accessing the education system and the labour market, among other relevant social roles and functions.

Social research can also provide insights into the consequences of the rapid expansion of so-called "assistive technology", which is designing and producing assistive devices that are changing the lives of PWD. It may also contribute towards improving these devices and understanding the factors regulating access to these devices, their impacts on daily life, and the social participation of people using them. On the other hand, social research in disability may also contribute towards solving problems related to the care provided by families to PWD, their impact on intra-family relationships, family activities for adapting to the situation, redistribution of roles and processes of family integration or disintegration. Social research may support the action, communication, structuring and organisational design of organisations working in disability and their relations with the State, families, PWD and other stakeholders in their environment.

In the sphere of social research, it is possible to analyse the processes of primary socialisation of children (in cases of congenital disability) and secondary socialisation in the case of adults (disability acquired through an accident or illness) or in the case of the elderly (disability due to ageing). It may also investigate the effects of these processes on the interaction of these people with the family, belonging and reference groups and social and organisational institutions. Research contributions that address the increase in longevity are also relevant. Contributions to understand and explain, for instance, the

social consequences of the medical science in prolonging the lives of people suffering from severe illnesses and chronic and disabling injuries, who live individually and socially limited lives. In other words, research on demographic and epidemiological issues is required, especially to learn about the geographical and social distributions of the multiple types of disabilities and the incidence or prevalence of disability by age, gender and ethnicity.

Moreover, many further issues related to the PWD's health care might interest social scientists studying health care systems, namely those related to how PWD use health care or how they are welcomed and treated in health care organisations. Cultural and social studies focusing on disability may also draw upon research focusing on victims and victimisation and violence processes affecting PWD, especially women. As research on the strategies and practices of the criminal justice and investigation system responsiveness to criminal actions and their impacts, namely regarding the factors causing impairment.

However, investigating through traditional social research methodologies is not enough. Researchers should favour emancipatory methodologies, ensuring the participation of PWD in the research that concerns them, in line with the motto of the internationally recognised Movement for Independent Living: "nothing about us without us". This movement showed how damaging the individualistic and biomedical approach to disability was and highlighted the importance of examining the experience of disability as perceived individually and collectively by PWD. When developing support or rehabilitation programmes, the interests and wishes of the individual are obviously of the utmost importance in establishing the plans. However, to assess the changes deriving from the implemented plans, we need to measure them objectively. That requires the participation of professionals or family members.

As the articles published here demonstrate, disability is above all a social and cultural issue, not a biomedical issue affecting a small part of the population, converted into a social minority, but one of the leading social phenomena of today, affecting societies as a whole. Considering the diversity of content in the papers published in this issue, we believe we live in a new era in the interaction between the disability domain and the scientific and social domains. Compared to the recent past, this era can be defined by growing scientific attention to disability issues and increased social attention to the problems of PWD. There are several signs of a consistent evolution in that direction. Still, this era is full of contradictions, ambiguities and ambivalence considering the continuous segregation, exclusion and low quality of life of PWD.

Despite this evolution, the truth is that, including the most developed countries, in cultural studies, including sociology and the social sciences at large, attention to disability as a scientific object took a long time to develop. In the Portuguese speaking countries, including Portugal, the scenario is still quite bleak, with disability issues far from

integrating social scientists' agendas. In fact, Portuguese speaking countries are lagging far behind countries such as the United Kingdom and France. In the United Kingdom, Disabled People International has been fostering cultural and social studies on disability for at least 30 years. It follows a theoretical model (social model), providing some practical guidelines to be developed to address the needs of PWD. The same in France through the activities of the Maison des Sciences Sociales du Handicap of the École des Hautes Études en Santé Publique. In Portugal, for instance, even though there is a state organisation dedicated to disability (Instituto Nacional para a Reabilitação, I.P.), there is no social sciences journal disseminating knowledge on this field. Apparently, neither other Portuguese-speaking countries have any formally established group (institute or university research centre) permanently investigating disability issues within the cultural or sociological studies. In fact, reviewing the literature on disability issues in Portuguese speaking countries, we can conclude that few researchers in these countries are permanently interested in the cultural and social issues of disability. We urgently need more and more research, as urgently as we need more and more inclusion. Through this issue of LJCS we are doing our part.

So, through an approach focusing on the critical theory of society, Michtelli Agra and Valdelúcia Alves da Costa, in "Inclusive Education Policies and Pedagogical Practices in Public Schools: Experiences in Brazil", analyse the implementation of public policies on inclusive education and the experiences of school inclusion of students with visual impairment in a public school in Niterói, state of Rio de Janeiro (Brazil). Its core objective is characterising the experiences on pedagogical praxis with visually impaired students in an inclusion context. Overall, the results of this paper aim at demonstrating that school inclusion of students with disabilities, to be effectively inclusive, requires a "collective political-pedagogical commitment from teachers, administrators and family members in favor of public schools" (p. 21).

The following article: "French Support and Work Assistance Establishment and Social and Professional Integration of Workers With Disabilities in Rural Areas. The Example of Habert (Savoie, France)", Meddy Escuriet, Mauricette Fournier and Sophie Vuilbert focus on the process of professional inclusion of a group of people with mental disabilities and/or intellectual disabilities in one French support and work assistance establishment located in a small rural and mountainous village in the Alps. According to the authors, this experience offers PWD compensation for their work. It is a therapy that promotes satisfaction with life and feelings of usefulness, social recognition and opportunities for independent living and community participation. The authors conclude that despite the professional inclusion being set in a rural environment in a rough territory and geographically distant from urban centres because the institution provides personalised mobility support, the geographical isolation may be a driver of professional social and spatial inclusion.

In "Inclusive Education Policies and Pedagogical Practices in Public Schools: Experiences in Brazil", Jaciete Barbosa dos Santos and Jenifer Satie Vaz Ogasawara,

drawing on the critical theory of society, especially the studies of Adorno, reflect on the paths of inclusive education. Despite social and political advances, in Brazil and many countries worldwide, they are still surrounded by physical, social and behavioural barriers that limit and cause multiple challenges to the educational process of PWD. Their path is still permeated by much precariousness, evident in the unavailability of resources and essential accessibility services and in the persistence of beliefs and attitudes that hinder the dignified educational inclusion of PWD. The authors conclude that creating a genuinely inclusive school requires looking beyond the specific needs of PWD. In other words, inclusive education also depends on the education systems' formation of individuals committed to valuing human diversity and accepting it unreservedly. Without this education, the inclusive school will only be a formal plan. The practices of discrimination, marginalisation and segregation will persist, and according to the authors, "we will be increasingly exposed to barbarism, resulting from a pseudo-formation/semi-formation that still prevails in most institutions" (p. 63).

The article that follows is "Professional Inclusion of Down Syndrome Workers in the City of São Paulo: Personal Achievement, Productivity, and Social Relationships in the Work Environment" by Ricardo Casco, Patrícia Ferreira de Andrade, Cintia Copit Freller, Gabriel Katsumi Saito and Roberta Cruz Lima. In this article, the authors introduce the results of a survey conducted in 2018, based on a sample of 20 young workers with Down syndrome. According to the authors' analysis of a set of dimensions related to the process of professional inclusion of the young people in the sample, it is possible to conclude that they are successfully included in the organisations' relational and work systems. The proof of this lies in the levels of satisfaction with work and the adequate performance of activities and tasks they undertake.

The article entitled "Effectiveness and Efficiency in Associations of Parents and Friends of the Disabled Persons From Minas Gerais" by Sérgio Sampaio Bezerra reveals some characteristics and portraits of the actions of the Associations of Parents and Friends of Disabled People in Minas Gerais (Brazil). These characteristics and portraits were drawn from the perspective of their managers, considering the three dimensions of these organisations' mission: offering services, improving the quality of services and defending the rights of people with intellectual disabilities. The author developed a laborious and careful methodological process and anchored in the principles of systemic analysis and using various statistical analysis techniques. He analysed the data from a random sample of 199 Associations of Parents and Friends of the Exceptional people aiming to measure the effectiveness and efficiency of these organisations' networks in Minas Gerais. The results obtained may, somehow, be considered surprising considering the heterogeneity of the network regarding the differences among the organisations in it, especially considering their location, size and variety of services provided to people with disabilities. In fact, unlike what might be expected, the statistical analysis results

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point to the network homogeneity. Hence, the author could not construct a quantitative explanatory model to understand the differences in the effectiveness and efficiency of the network organisations' actions.

In the article "Thematization of Disability in Children's Literature – Perspectives on the Characters", Renata Junqueira de Souza and Sílvia de Fátima Pilegi Rodrigues analyse how people with physical disabilities are represented in six children's literature books. It is a relevant debate, given the goals of inclusion of children and young people with physical disabilities, where the objectives of the Brazilian national special education policy intersect with how children's literature publishers interpret these goals in their published works. The works the authors analysed depict the characters with disabilities in two different mindsets. On the one hand, the not very inclusive approach looks at disability through the lens of political correctness and stereotypes PWD. This approach represents them as subjects, both capable of heroic overcoming and accepting, pure and simple, the limitations of the situation they find themselves in. On the other hand, an inclusive approach looks at disability through a human diversity lens, treating disabled characters equally with non-disabled ones. In this approach, overcoming and accepting reality inspire the characters' interactions in the stories presented. The authors conclude that "it is relevant to analyse works that neither reinforce stereotypes placing the characters in conditions of subordination and/or inspiring pity, nor refer to disability as heroic overcoming, resignation and acceptance of destiny or divine will" (p. 135).

In the article "Professional (Re)Integration of Persons with Disabilities: Perceptions of the Contract Employment Insertion/Contract Employment Insertion+ Measures by Beneficiaries and Promoters", Neuza Cardoso Borges and Paula Campos Pinto question the Portuguese State's policy to promote the employability of people with disabilities and its results. Hence, the authors present and discuss

> the results of an exploratory and qualitative study on the measures known as contract employment insertion/contract employment insertion+ (CEI/CEI+), implemented in the region of Lisbon and the Tagus Valley. It examined the perception of three stakeholders — 16 male and female beneficiaries with disabilities, nine institutions promoting these measures, and seven non-profit organisations devoted to training and employment of persons with disabilities — to know their perspectives on the potentialities and limitations of these measures. (p. 139)

The authors conclude that, although the analysed measures positively affect the well-being of the people involved who consider them as good opportunities to show their professional skills, they do not solve the employment needs of people with disabilities successfully permanently. The article is closed with a list of recommendations, based on the testimonies of the stakeholders involved, that we consider a relevant contribution to the analysed measures' greater effectiveness.

Finally, in "Workers With Down Syndrome: Autonomy and Wellness at Work", Alex Sandro Corrêa, José Leon Crochick, Rodrigo Nuno Peiró Correia and Fabiana Duarte de Sousa Ventura describe how the professional inclusion of a sample of workers with Down syndrome impacted their quality of life. The impacts are manifold and can be observed at various levels: individual, social and affective relationships and expectations for the future. The authors report improvements in well-being, self-esteem and autonomy and other "achievements in the affective-social field (dating and friendships), in the family, economic and professional spheres, albeit with restrictions" (p. 157). Furthermore, employment also led to improvements in their feelings of worth, acceptance by others and projecting the future in the same way as other young people of the same ages.

The "Varia" section includes three articles. The first by José Ricardo Carvalheiro has the title "'The People Turn it Off and Go Out Looking for Fado' — Radio and the Fado Resistance to the Estado Novo in the 1930s". Essentially, the author seeks to identify the articulations of radio with Fado throughout the 1930s, a period marked by the rise of Salazarism in Portugal. These articulations might be considered the result of struggles for the domination of radio broadcasting among different actors, with different purposes and their own strategies. The second article, "World Out of Place: The Degradation Trajectory of Holiday Building From the Perspective of Bourdieusian Social Space" by Victor Lucena and Julieta Leite is, according to the authors, "a reflective analysis of the biographical trajectory of symbolic degradation of an emblematic edifice built in Recife (Brazil) — the Holiday Building" (p. 193). Finally, the "Varia" section includes Olga Estrela Magalhães, Clara Almeida Santos, Catarina Duff Burnay, Rita Araújo, Felisbela Lopes and Ana Teresa Peixinho's article with the title "Vaccination Against Covid-19 — An Analysis of Portuguese Official Sources' Digital Health Communication". In this article, the authors analyse and assess how the Portuguese State and the Portuguese health organisations communicate with their audiences through digital media in a time characterised by the health crisis caused by the covid-19 pandemic. They collected digital content published on five websites and four online social networks. This compilation was undertaken between the day the approval of the first vaccine was announced and when health professionals started administering the second dose. The results merely provide informative information, lacking the pedagogical content required to engage and empower the recipients.

Translation: Anabela Delgado

References

Convenção sobre os direitos das pessoas com deficiência, Dezembro 16, 2006, https://www.inr.pt/convencao-sobre-os-direitos-das-pessoas-com-deficiencia

Ravaud, J.-F., & Stiker, H.-J. (2000). Les modèles de l'inclusion et de l'exclusion à l'épreuve du handicap. 1re partie: Les processus sociaux fondamentaux d'exclusion et d'inclusion. *Handicap - Revue de Sciences Humaines et Sociales*, 86, 1–18.

Turner, V. (1990). *Le phénomène rituel. Structure et contre-structure*. PUF.

Van Gennep, A. (1981). *Les rites de passage*. Picard.

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THEMATIC ARTICLES | *ARTIGOS TEMÁTICOS*

Inclusive Education Policies and Pedagogical Practices in Public Schools: Experiences in Brazil

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Abstract

This article refers to the results of a survey on policy implementation of public policies for inclusive education and the experiences of school inclusion of students with visual impairments at the Adelino Magalhães Municipal School, located in Niterói, state of Rio de Janeiro, with the primary objective of characterizing the experiences on pedagogical praxis with students with visual impairments considered to be in a situation of inclusion. The theoretical-methodological framework adopted in the problematization of the object of study and data analysis was the critical theory of society. The study included: two visually impaired students considered to be in a situation of inclusion, a teacher from the inclusive classroom, a teacher from the multifunctional resources room and a teacher of pedagogical support for school inclusion. The results revealed that the Adelino Magalhães Municipal School is developing inclusive education, mainly due to the implementation of public education policies in the municipality of Niterói, which prioritize the inclusion of students with disabilities. It was found that inclusive education demands collective political-pedagogical commitment from teachers, administrators and family members in favor of public schools and their democratization. Consequently, inclusive education enables solidary teaching and learning experiences centered on the humanization of students with disabilities, thus making them able to recognize themselves as participants in society, in which the violence present in competitiveness prevails.

Keywords

public policy, inclusive education, pedagogical praxis, public school

Políticas de Educação Inclusiva e Práxis Pedagógica na Escola Pública: Experiências no Brasil

Resumo

Este artigo refere-se aos resultados de uma pesquisa sobre a implementação de políticas públicas de educação inclusiva e as experiências de inclusão escolar de estudantes com deficiência visual na Escola Municipal Adelino Magalhães, localizada em Niterói, estado do Rio de Janeiro, e tem por objetivo central caracterizar as experiências sobre a práxis pedagógica com estudantes com deficiência visual considerados em situação de inclusão. O referencial teórico-metodológico adotado na problematização do objeto de estudo e análise dos dados foi a teoria crítica da sociedade. Participaram do estudo: dois estudantes com deficiência visual considerados em situação de inclusão, uma professora da sala de aula inclusiva, uma professora da sala de recursos multifuncionais e uma professora de apoio pedagógico à inclusão escolar. Os resultados revelaram que a Escola Municipal Adelino Magalhães está desenvolvendo a educação inclusiva,

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sobretudo em decorrência da implementação das políticas públicas de educação no município de Niterói, que estabelecem como prioridade a inclusão escolar de estudantes com deficiência. Foi constatado que a educação inclusiva demanda compromisso político-pedagógico coletivo de professores, gestores e familiares em prol da escola pública e de sua democratização. Consequentemente, a educação inclusiva possibilita experiências de ensino e aprendizagem solidárias, centradas na humanização de estudantes com deficiência, tornando-os, assim, aptos a se reconhecerem como partícipes da sociedade, na qual impera a violência presente na competitividade.

Palavras-chave

políticas públicas, educação inclusiva, práxis pedagógica, escola pública

Introduction[1]

In the current civilising stage, inclusive education is a struggle not exclusively for public policies, which guarantee the access of students with special educational needs to public schools; but also by the transformation of society marked by the struggle between capital and labour, social hierarchy and competitiveness, marks of the managed society. In this sense, individuals considered more robust and, consequently, more able to compete in class society are ranked hierarchically above individuals from the so-called social minorities, such as people with disabilities and other individuals with physical, sensory and physical characteristics considered deviant of the standard imposed by the administered society.

The theoretical-methodological framework of this study is the critical theory of society, emphasising the thought of Adorno (1970/2010). According to this author, we consider that "education has meaning only as education directed to a critical self-reflection" (p. 121) and "the demand that Auschwitz is not repeated is first of all for education. In such a way it precedes any others that I believe it is neither possible nor necessary to justify it" (p. 119). Therefore, it was necessary to discuss: does school education contemplate human demands and the need to face the social violence manifested at school? Society's critical theory contributes to this discussion, especially in the elaboration of the past so that the worst that happened — barbarism — is not repeated:

> which is to say that memory, time and remembrance are liquidated by bourgeois society itself in its development, as if they were a kind of irrational remainder, just as the progressive rationalisation of industrial production procedures eliminates along with the other remnants of artisanal activity also categories such as learning, that is, the time of acquisition of experience in the craft. When humanity alienates itself from memory, exhausting

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[1] This article is part of a master's thesis in education developed at the Fluminense Federal University, on the implementation of public policies for inclusive education and the experiences of school inclusion of students with visual impairments at the Adelino Magalhães Municipal School, located in Niterói, state of Rio de Janeiro, with the main objective of characterizing the experiences on pedagogical praxis with students with visual impairments considered to be in a situation of inclusion (Agra, 2015).

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itself breathlessly adapting to the existing, this reflects an objective law of development. (Adorno, 1970/2010, p. 33)

In order to admit the possibilities of education against violence, given the objective conditions in force, it would be ideological to attribute such responsibility exclusively to school professionals, disregarding the current social structure:

> the dominant ideology nowadays defines that the more people are subjected to objective contexts in relation to which they are powerless or believe they are powerless, the more they will make this powerlessness subjective. In keeping with the saying that *everything depends solely on people*, they attribute everything that depends on objective conditions so that existing conditions remain untouched. In the language of philosophy, we could say that the people's strangeness in relation to democracy reflects society's alienation from itself. (Adorno, 1970/2010, p. 36)

In this context, this article aimed to analyse the inclusive education policy actions and praxis in the pedagogical organisation of the Adelino Magalhães Municipal School and the inclusive education policies in the municipality of Niterói, Rio de Janeiro, Brazil, considering that the Brazilian official documents and international declarations advocate the right to education. Two students with visual impairment participated in this study, a teacher from the inclusive classroom (IC) and a teacher from the multifunctional resources room (MRR), a space to support school inclusion. According to Alves et al. (2006), the MRR has specific material to meet students' differences and learning needs. This space stands out for the "development of learning strategies, centred on a new pedagogical practice that favours the construction of knowledge by students, subsidising them to develop the curriculum and participate in school life" (Alves et al., 2006, p. 13), and, even more, it is necessary to consider the participation of a teacher to provide pedagogical support (PS) for school inclusion in the school[2].

The Adelino Magalhães Municipal School is located in the municipality of Niterói, state of Rio de Janeiro and offers the following architectural adaptations: wide doors and specific school desks for right-handed and left-handed students. We also identified some technological resources of communicational accessibility and alternative communication for students with cerebral palsy, such as communication boards, digital game and music platforms, Brazilian sign language interpreter (Libras), teaching material for writing and reading through the Braille system and voice programs for computers.

Concerning elementary school, 25 students, with a report proving the type of disability to participate in the specialised educational service[3], benefit from the MRR, with

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[2] The Brazilian Inclusion Law (Lei Brasileira de Inclusão da Pessoa com Deficiência, 2015) refers to the school support teacher in item XIII as follows "school support professional - person who performs food, hygiene and mobility activities for students with disabilities and works in all school activities in which it is necessary, at all levels and modality of education, in public and private institutions, excluding techniques or procedures identified with legally established professions".

[3] According to Decree No. 7.611 (Decreto n° 7.611, 2011), in Article 3, "the objectives of specialized educational care are: I - to provide conditions for access, participation and learning in regular education and to guarantee specialized support services according to the individual needs of the students; II - guarantee the transversality of special education actions in regular

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14 inclusive classes in the school, counting the morning and afternoon shifts; with the participation of 14 teachers. The school also has teachers who provide PS for the special educational needs of students considered in a situation of inclusion. In addition to the two students with visual impairment considered to be in a situation of inclusion, there are also students with hearing impairment/deafness, physical impairment/cerebral palsy, mental impairment/Down syndrome, autistic spectrum syndrome, attention deficit hyperactivity disorder, hydrocephalus, oppositional and defiant disorder, tuberous sclerosis and hemiparesis.

Students with visual impairment have low vision, are twins and attend the afternoon shift. The school is organised with a maximum of two students considered to be in a situation of inclusion per class. Because, among the 14 classes with students considered in a situation of inclusion, two have three students with disabilities, in line with the reference group[4] recommended for elementary education under Article 10 of Portaria FME nº 878/2009 (2009). It is noteworthy that the establishment of the reference group refers to the implementation of pedagogical, organisational strategies to provide sustainability to the school inclusion of students with disabilities. Therefore, stressing the school that has historically been segregated, as stated by Costa (2007), "well, it doesn't cater to human diversity; educates for homogenisation; adaptation; and social reproduction; disregards human and learning differences; reproduces the logic of dominant capitalist production; ranks students by assessment and failure, among others" (p. 7).

That said, it is urgent to problematise the school as a social instance that reproduces the capitalist logic by imposing barriers to the access and permanence of students with disabilities in school, by promoting a hierarchisation of individuals concerning those able or incapable of learning, preventing the possibility of a welcoming formation of human difference and, consequently, a democratic education based on human rights. Thus, inclusive education can be affirmed when the school becomes a participant in the democratisation of education by designing and implementing a pedagogical project that addresses the philosophical and political foundations of human and democratic education and, thus, opposes teaching attitudes and practices discriminatory teaching methods. From this perspective, Leme and Costa (2016) affirm the daily pedagogical practice and the interrelationships between students at school as the epicentre of the inclusion process:

> considering that the inclusion process materialises in the school, with regard to education, we defend the articulation between policies and praxis since the affirmation of public policies for inclusion in education is linked to the daily experiences of students in schools. Therefore, in everyday school life, participation and the full range of learning experiences experienced by

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education; III - foster the development of didactic and pedagogical resources that eliminate barriers in the teaching and learning process; and IV - ensure conditions for the continuity of studies at other levels, stages and teaching modalities".

[4] The reference group, in accordance with Portaria nº 878 (Portaria FME nº 878/2009, 2009), is defined in Article 4, as being "the group of students organized at the beginning of each academic term, through the process of grouping" (para. 1).

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students are defined, which can contribute to emancipatory and inclusive
human development. (p. 669)

In short, it is at school and in the daily experiences of students with disabilities along with other students without disabilities, teachers, pedagogical and school management teams, that inclusive education can become a possibility for coping with and overcoming violence, especially that manifested by prejudice against students considered to be in a situation of inclusion. Therefore, the demand for studies that analyse the experiences of students with visual impairments at school.

Experiences of Visually Impaired Students in the Pedagogical Routine of Adelino Magalhães Municipal School

This study opted to adopt pseudonyms (Paulo and Pedro) to preserve the privacy of students with visual impairments. These students attend the same fifth-grade elementary school class, in which a student with autistic spectrum syndrome is also studying, accompanied by a teacher who provides PS for school inclusion. Paulo and Pedro turned 14 years old in 2014 and entered the school in 2012, coming from a private school.

In classroom organisation, both Pedro and Paulo occupy the front row. Because, when they were evaluated by the special education team of the municipality of Niterói, some recommendations were necessary, such as using the inclined plane and the notebook with extended guidelines, 6B pencil that guarantees stronger writing, aiming to support reading and writing, in addition to the collaboration of the teacher who works in the IC in the general aspects related to the classes. For example, the teacher asks the school board to enlarge the pages used in the textbook when there is a need to study a specific page.

According to the reports of the MRR teacher, Pedro and Paulo, at the beginning of the school year, resisted participating in the proposed pedagogical activities, stating that "they interacted well when they were in this room, but asked that the door be kept closed, claiming not to like to be seen in a room for PS for school inclusion for students with disabilities" (teacher Nilza[5], MRR). These students even asked about the reason for participating in the specialised educational service in the MRR.

In the IC[6], the teacher reported that Pedro and Paulo had difficulty using the inclined plane, demonstrating that they did not like to use it, complaining when the teacher asked for an expansion of the textbook pages. Pedro and Paulo reported, at all times, the desire to carry out the tasks in the book itself, like the other classmates. The teacher was also careful to expand the tests and activities and, when writing on the chalkboard, she always adopted an enlarged letter.

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[5] Participants in this study are identified by pseudonyms to preserve privacy

[6] In which students considered to be in a situation of inclusion study together with students without disabilities and/or special educational needs.

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Thus, inclusive teaching attitudes in meeting students' learning demands in a situation of inclusion are necessary to support their learning and develop solidarity with other students. For Crochick et al. (2011): "in this way, the relationships of students among themselves, with a greater or lesser degree of discrimination, also depend on how teachers act with all their students" (p. 197).

Regarding the MRRs, in the municipality of Niterói, it is worth noting that the service to students considered to be in a situation of inclusion occurs in the same period as the pedagogical activities of the IC, contrary to Decree No. 7611 (Decreto n° 7.611, 2011), to prescribe that specialised educational services take place after classes in the IC. Some reasons to justify the service mentioned above in the same shift of classes in the IC, narrated by the research participants, were "lack of financial resources for food, school transport, professionals at the school and the dynamics of the school's functioning".

In this sense, students considered to be in a situation of inclusion, who receive specialised educational care in the MRR, are removed from the IC at a time agreed between the teachers. According to teacher Nilza (MRR), Pedro and Paulo, who were not comfortable at the beginning of the school term, changed their behaviour as the days went by and started to participate actively in pedagogical activities. That provoked other students' interest in participating in these pedagogical activities, with the IC teacher having to justify not being possible for all students to participate. Therefore, it is possible to admit Pedro and Paulo's reason for participating in pedagogical activities in the MRR without feeling discriminated against. That expresses the importance of universalising access to PS at school, making it inclusive for all students.

Therefore, we affirm that, even though Pedro and Paulo have changed their attitude of resistance to specialised educational care in the MRR at the same time as classes in the inclusive room, it is not pedagogically adequate because they no longer participate in the activities in the IC, interrupting the development of their learning process in a collaborative and challenging environment. Thus, in addition to the justification for inclusive education (concerning specialised educational care) of students with disabilities considered to be in a situation of inclusion, not complying with Decree No. 7.611 (Decreto n° 7.611, 2011), it is worth asking: How can this distortion of specialised educational care be overcome in the MRR after shift time? Results of studies, considered by Crochick et al. (2011), provide elements that contribute to the understanding of what happens in public schools in Niterói (Rio de Janeiro):

> by analysing 20 surveys that studied the attitudes of students from regular classes, which included students considered to be in a situation of inclusion, Klingner and Vaughn (1999) concluded that students with or without difficulties want equal treatment from teachers and the school, that is, they want everyone to undergo the same activities, the same books and have the same group activities. They don't mind that the teacher adapts methods or spends more time explaining something to students who could not understand a particular subject, because, according to them, this way they have

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> a chance to learn more and better. They like to help colleagues who have more difficulties and, with exceptions, prefer group work that contains students with and without difficulties. Thus, inclusive education should not be concerned only with the issue of socialisation because, in addition to what the work of Klinger and Vaughn informs, if the individual is formed through the incorporation of culture (see Adorno, 1959/1972), it must be transmitted so that everyone can differentiate through it. (p. 200)

In this context, it is understood that the participation of students, considered to be in a situation of inclusion, in the IC should not be interrupted for specialised educational care in the MRR, but rather take place after a shift as provided for in Decree No. 7.611 (Decreto n° 7.611, 2011). It should also be noted:

> according to Monteiro and Castro (1997), research shows that students without disabilities tend to become more supportive. These data indicate a central point in the debate on inclusive education, which cannot be left unstated. On the other hand, the division of opinions found may indicate the little discussion about inclusive education in our environment. (Crochick et al., 2011, p. 207)

That said, it is possible to affirm that inclusive education can contribute to the teaching and learning of all students by promoting formation experiences in a collective, collaborative and solidary way. Thus, in the daily life of the MRR, several playful activities are developed, of which we highlight some. First, we present the material used: four large cards with pasted figures, materials the teacher made herself and letters enlarged. The proposed activity was the choice of one of the cards containing from three to four figures to put together the name of each one of the figures.

Teacher Nilza (MRR) reported that the most significant difficulty for both Pedro and Paulo is reading and writing, so, no matter how short their time in that room, she always plans and develops reading activities and writing. During the activity, it is noticed that Pedro and Paulo carry out the activity in partnership, even though each one is developing their own card. Both demonstrate difficulties writing words in current use in Portuguese for fifth-grade students. When they miswrite a word, the teacher asks: "is this the way you spell it?". Thus, Peter and Paul are given the opportunity to think about the writing of the word and carry out the correction to be written properly.

Paulo is shyer and focused, while Pedro is talkative and complains about the activity and asks to finish later. However, he manages to complete the activity before Paulo. Thus, both complete the activity in their own time and with their own questions and doubts. Based on these observations, it is necessary to propose individual moments in specialised educational care for each student, to carry out activities focused on their educational needs. It is noteworthy that even being twins, their educational demands are different. After the first activity, Pedro and Paulo asked the teacher for a "memory game" activity. They went from a cooperative moment to a competitive moment in this activity.

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In this sense, Becker (as cited in Adorno, 1970/2010) states:

> evidently, one could defend the thesis that it is necessary to prepare for competition at school for a competitive society. Quite the contrary, I think the most important thing that the school needs to do is to provide people with a way of relating to things. And this relationship to things is disturbed when competition is put in its place. (p. 163)

In this way, competitiveness does not contribute to affirming the inclusive teaching-learning process. It strengthens the hegemony of capital in class society and thus, establishes a priori which individuals are more and/or less able to self-preservation and reproduction, of capital that does not aim at the inclusion of all individuals. Education has, as a central status, this excluding logic, which according to Adorno (1970/2010), does not collaborate with a possible debarbarization through of education, since in the competitive process, the human being experiences different forms of failure that generate guilt, which can turn into aggression. Thus, it is understood that collaboration, on the other hand, expresses a human need to relate to one another, regardless of sensory, cognitive and physical differences.

In this sense, inclusive education can help combat violence by integrating itself into a democratic school project. To this end, it is urgent to consider human differences as necessary for the subjectivation of students, so that they are formed as free-thinking individuals and, in these terms, the teacher's responsibility lies, above all, in the dimension of the inclusion of students, with or without disabilities, creating challenging and diverse teaching environments.

The Teaching Responsibility for Inclusive Education in Daily School Life

The teacher's teaching activities gain visibility by analysing the daily school life of students with visual impairments in public schools. Even if the school has specialised teaching materials and technological resources to meet the educational demand of students considered in inclusion situations, the teacher must be receptive to live new pedagogical, such as the challenges related to inclusive education in public schools. That is essential to make these students feel involved and respected as individuals with physical, sensory and cognitive differences and that these differences constitute their subjectivity.

Consequently, the welcoming attitudes of teachers contribute significantly to allowing them to live inclusive pedagogical experiences that require more of their sensitivity than the use of didactic and technological resources. In this way, the teaching performance can be considered possible beyond the transmission of curriculum content and the use of material resources, seeking to meet the learning and development demands of students, among those considered to be in a situation of inclusion. We think this is possible, even considering the limits of education under the aegis of capital in managed society. In this regard, Crochick et al. (2011) contribute to this understanding:

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the implementation of inclusive education is important in the struggle for a fairer society, but we must not disregard the limits of current education with regard to formation due to their own objective conditions. This implies the need for more than just the inclusion of minorities previously segregated from regular schools; the need to also be concerned with the quality of education and with how much this currently contributes to forming effectively critical individuals. If the criticism is related to the possibility of a fairer society, and, if possible, just, living with discriminated minorities is already a formative element. The teacher's role in this formation is fundamental, as it is not just about transmitting knowledge but how it is done and its relationship with knowledge. The form of transmission understood here does not refer only to techniques, even if they are essential, but to the teacher's engagement, to his complicity with the student's learning, that is, it refers to political and ethical principles. (p. 196)

Consequently, inclusive education demands articulation with conscious and democratic attitudes on the part of the teacher. Above all, about understanding the urgency of welcoming diversity at school. Therefore, teacher formation should not be disregarded, and support for their pedagogical activities favours school inclusion and students with disabilities who are considered a priori unsuitable for school learning.

This study carried out a semi-structured interview with the following teachers: from the MRR, from the PS to school inclusion and from the IC. The narratives of the participating teachers contributed significantly to characterising the school and the process of school inclusion of students with visual impairment and the teachers' attitudes towards inclusive education.

According to the data collected, it is noteworthy that, through the semi-structured interview, it was identified that the participating teachers had lived previous teaching experiences with students considered to be in a situation of inclusion with special educational needs. However, never before with visually impaired students.

Teacher Nilza (MRR), working in the MRR since 2009 at the Adelino Magalhães Municipal School, had the opportunity to work with visually impaired students for the first time in 2012. As for the teacher in the IC, Albertina received students Pedro and Paulo in 2013, who continued studying in the same class in 2014, having been her first teaching experience with visually impaired students considered to be in a situation of inclusion.

Regarding the question, "what do you think about your initial formation (undergraduate degree) about students with special educational needs? Did it contribute with subsidies to your inclusive teaching performance? Why?", it was identified that teacher Nilza (MRR) did not study about the education of students with special educational needs in the undergraduate degree course. Because, as she completed her initial academic formation in 1985, it is clear that there were no subjects in these courses on education for students with special educational needs and inclusive education.

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Teacher Albertina (IC) narrated that she did not study in her undergraduate course curricular contents that addressed topics such as "special education", "inclusive education", "students with special educational needs", even though she completed two qualifications in pedagogy, school administration and teaching in the grades initials. Bruna, a teacher of PS for school inclusion, reported having had few opportunities to access information on the topic of special and/or inclusive education, although she believes it was important to her formation. Therefore, the teachers participating in the study had few learning opportunities in their initial formation in the pedagogy course on the themes "special education" or "inclusive education", which can cause more significant challenges for teachers in the face of inclusive education for students with visual impairment.

As for the question "have you ever attended any specialisation and/or improvement course that has considered issues related to students with visual impairment?", we obtained the following narratives: "my specialisation was in psychopedagogy. I took several courses and participated in workgroups, seminars and lectures on visual impairment" (teacher Nilza, MRR); "no, only at the university we work for a few moments discussing these issues and so many others" (teacher Bruna, PS).

> Because I thought I had little knowledge about school inclusion and saw the number of students with educational needs increase every year, I tried to participate in the postgraduate course in inclusive education. I am currently conducting a distance learning course on this topic. Specifically about visual impairment, as I have not had the opportunity to take this course before. (Teacher Albertina, IC)

According to the narratives of the participating teachers, it was found that teacher Nilza, who works in the MRR, participated in a course on visual impairment and, as for teacher Bruna, who works in PS for school inclusion, she revealed that she did not have access to no course in his teaching practice so far. However, during his degree course, she had the opportunity to approach the theme of school inclusion. Teacher Albertina (IC) has developed knowledge about inclusive education in her teaching activity. In this sense, it is possible to affirm that the participating teachers support inclusive education, which has contributed to the access and permanence of Pedro and Paulo, students with visual impairments, at Adelino Magalhães Municipal School.

The next question refers to the importance teachers attach to theoretical studies in their formation. Unanimously, they affirmed that theoretical studies are essential. Teacher Nilza (MRR) narrated that theoretical studies contribute to expanding her knowledge and teacher Albertina (IC) highlighted that "theoretical studies are like a starting point, a foundation for the pedagogical praxis, making theory concrete". Teacher Bruna (PS) narrated: "theoretical studies are always important in our pedagogical routine, and from them, we can project our pedagogical future. Therefore, they are always valid". We observe in these narratives the reference to the "pedagogical future" intimately articulated to the theory as if the theory answered exclusively later questions. The challenge

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posed to teachers to understand in theory what can meet the pedagogical issues present in everyday school life is noticeable. These narratives reveal that theory is split from praxis. Adorno (1969/1995) opposes this split stating, when resorting to Kant and Fichte, "thinking is acting, a theory is a form of praxis" (p. 204).

Thus, it is noteworthy that the teacher, as a product of society, split between capital and work, considers the theory to be distinct from praxis, in which education has historically focused on serving individuals according to their position in the social stratum. In this regard, Crochick et al. (2011) analyse the "production of mass education" that aims to prepare individuals to deal with technology in the world of capitalist work:

> technology has not failed to enter education, which, in its drive to train for competence, has created methods and simplified knowledge so that teachers can be dispensed with, it has become a transmitter of information and no longer conducive to the formation that will go beyond what exists. This is consistent with Benjamin's (1938/1989) description of the transformation of experience into living throughout the 19th century: the experience does not leave marks on the individual; and, according to Adorno (1959/1972), the information is soon replaced by new ones: it has to be updated at all times, but as the knowledge needed to deal with machines – whether material or human – is soon surpassed and the experience that cannot do without the Kantian precept: "an I that accompanies all my representations" has no place, weakly constituted individuals emerge. (p. 194)

Consequently, it promotes formation that does not aim at the totality and development of the various dimensions of students, in order to contemplate their differentiation as free-thinking individuals, instead of "standard citizens" and instrumentalised to meet production in the conservation and reproduction of society where the logic of capital, competitiveness and the exclusion of individuals considered incapable of meeting the dictates of this society prevails.

This weakness in the individual's constitution directly impacts the teacher's pedagogical work, as previously stated. The experiences do not occur, giving way to mere contacts that do not leave formative marks on the individual. Therefore, it does not support its humanisation. When we asked "tell us about your experience with inclusive education concerning students with special educational needs who are considered to be in a situation of inclusion. Does something tickle you?", the teachers narrated: "I see that things still need to be straightened out. But, it's a good start. *Soon, new times will be arriving, and everything can get even better* [emphasis added]" (teacher Bruna, PS).

> The experiences that I live daily are very rich for my work. There are several types of students and their disabilities that attend the multifunctional resource room. Such as autistic and Down spectrum syndromes, low vision, hearing loss, attention deficit hyperactivity disorder and others. Every day I'm improving my knowledge and increasing the challenges this work takes

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me. *What instigates me is this daily struggle to conquer spaces for these students* [emphasis added] in a society where not everyone has the same approach to people with special educational needs. (Teacher Nilza, MRR)

When I first received a student with special educational needs, I realised I didn't know anything about it. I initially had difficulties understanding and understanding the student's special learning needs. He was extremely agitated, and the other students couldn't concentrate on the activities they needed to do. I made several mistakes and successes. *However, the number of correct answers increased from the moment I started talking, almost daily, with this student's mother* [emphasis added]. So, I began to understand his reactions, and I learned to relate to him better, following his mother's instructions. Therefore, I find the partnership between the family and the school very interesting and extremely important for the benefit of the student. (Teacher Albertina, IC)

In these narratives, it is clear that teachers are involved with inclusive education. However, by highlighting these phrases, the intention is to draw attention to some aspects: the first narrative shows the teacher's dissatisfaction with the current state of inclusive education. However, dissatisfaction does not seem to take her out of her comfort zone, which reveals something challenging in her pedagogical teaching practice. Perhaps this is what Adorno (1970/2010) would call "self-blame underage" when resorting, once again, to Kant: "stating that this state of underage is self-blame when its cause is not lack of understanding, but the lack of decision and courage to use understanding without the guidance of others" (p. 169).

In teacher Nilza's (MRR) narrative, the experience with students with special educational needs gains visibility and, according to the teacher, enriches her pedagogical work. We have to question: to what extent can this experience contribute to its own humanisation? When we learn to accept and respect human differences, it is possible that we also accept ourselves and, possibly, the world can be considered as being welcoming and human.

Thus, we agree that the daily struggle is necessary for our humanisation and respect for human differences. The school, considering the limits of education, remains the space in which it is possible to train autonomous and emancipated students, corroborating the thought of Crochick et al. (2011):

what can be done is, according to Adorno (1967/1995), to insist that education be geared towards resistance to the oppression of men, so that it is an education that leads to the perception of social contradictions, and not to deny it. Of course, only with education it is not possible to change society, however, through it, it is possible to strengthen the individual conscience so that it opposes violence. (p. 196)

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Opposition to any and all forms of violence is the principle for inclusive education. In teacher Albertina's (IC) narrative, the expression "talk" stands out. Initially, the teacher felt insecure about meeting the educational needs of students with visual impairments, having faced the challenges of teaching and learning from an inclusive perspective. The teacher decided to understand and meet the students' individual learning needs and, to that end, established a permanent dialogue with their families. So, it became possible to advance in the process of school inclusion of students and, at the same time, to reflect on their praxis. For, it is what may provide the breakthrough in excluding, hierarchising and segregating education. The family, in this case, is present, which benefits the process of school inclusion of students with visual impairments and the adaptation of the teacher in the IC.

As for the question about the experience in working with students with visual impairments at Adelino Magalhães Municipal School, some questions become relevant. First, regarding the work developed in the IC, teacher Albertina reports that students with low vision "do not accept this deficiency and, even less, the fact that it is progressive"[7] and that teacher of PS who is in the IC is not accepted by them either. So, because she has a good relationship with these students, she tries to give them the PS they need. As for the challenges faced in the pedagogical routine with students with visual impairment, teacher Nilza (MRR) narrated:

> it's a challenging and very enchanting experience. Because, despite having low vision and not profound blindness, they have many difficulties in teaching and learning. I do adapted activities, despite having very varied material. I put into practice the knowledge I acquired in improvement courses so that students can overcome the barriers found in their daily lives.

In turn, teacher Bruna (PS) stated: "it has been a great and very productive experience. In a few moments, I even copied it for him, but only to encourage him". In these narratives, there is an interaction between teachers in the IC, in the MRR and students with visual impairments. However, the teacher's narrative of PS for school inclusion is dissonant. She states that in some moments, she developed the learning activity by the student. Students do not need the teacher to carry out their learning activities for them. However, it is noteworthy that this teacher may also need the knowledge to identify her pedagogical attributions at school concerning PS for school inclusion.

Despite being designated in the class to be with a specific student, the teacher of PS for school inclusion, is not a teacher exclusively for that student but the class. Therefore, the referred teacher needs to know that supporting a student is not performing school activities for him, exempting him from the learning process. Such an attitude will not contribute to the development of your educational development. Instead, it will

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[7] According to the medical assessment made available to the school, together with the assessment carried out by the municipality's special education team, students with low vision, participating in this study, have a vision pathology that tends to progress over time, with the possibility of blindness.

be contributing to its heteronomy, which inclusive education must oppose. As for the interaction between the IC and the MRR, teacher Nilza (MRR) says:

> it happens in the best way. As I work on the shift in which students with low vision study, I am always in contact with the inclusive classroom teacher. We exchange ideas and information aimed at solving the difficulties that arise. I follow, through it, the content that is being worked on and make my adaptations. Everything is well articulated with no problem.

In this regard, Crochick et al. (2011):

> Beyer (2005) and Pacheco et al. (2007) emphasise, in relation to the discussion on inclusive education, that joint work between teachers is important in this area, which Booth and Ainscow (2002) also advocated. For these authors, it is not about defending the presence of an assistant in the classroom, but about the joint work between teachers. (p. 212)

Consequently, the collaborative work between teachers in the IC, PS for school inclusion and the MRR contributes to the development of pedagogical activities by focusing on meeting the specific educational needs of students with and without disabilities.

When we asked teachers to give statements about the pedagogical challenges faced in teaching activities with visually impaired students, both in the MRR and in the IC, the pedagogical involvement between the MRR and the IC teachers' was identified. On the other hand, the teacher of PS for school inclusion expressed difficulty working with students: "I have no experiences to report, as the time I spend with Pedro and Paulo is very little" (teacher Bruna, PS).

During observations at the Adelino Magalhães Municipal School, it was noticed that the teacher of PS for school inclusion in the IC does not bother with the situation and ends up becoming practically exclusive to the student with autism spectrum syndrome. By not trying to change this situation, it ends up saying to the students, in general, that she is not a PS teacher in the class, which is recommended by the guidelines regarding the role of the PS teacher for school inclusion in an IC. In this regard, it is worth highlighting the narrative of teacher Albertina (IC),

> my students with low vision perform the same activities as the rest of the class. However, with a differentiated dedication to serve them according to their needs, that is, all the written material provided to the class must be expanded for them (tests, exercises, textbook pages and handouts).

Stand out in the expression: "my students". It is interesting to observe how the IC teacher takes responsibility for these students. It was also identified that students with visual impairments interact with non-disabled colleagues, demonstrating that they are participants in the classroom, that is, they are not at the mercy of classroom dynamics and, as teacher Albertina (IC) stated, "of students with visual impairments it is required in a similar way to other students, with the necessary adaptations to meet their

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special educational needs", which is in line with the principles of inclusive education, as highlighted by Crochick et al. (2011) about its importance of the positive attitude of the teacher in the classroom in the affirmation of inclusive education:

> certainly, the teacher is the main agent in the classroom, and much of what may affect students without disabilities in relation to those who have them depends on their attitudes. Thus, the experience of contact with students with disabilities is not enough for some degree of inclusion to occur; the consequent intervention of the teacher is also necessary. (p. 198)

Thus, the teacher's intervention becomes central in the school inclusion process so that students with disabilities and without disabilities are guided in developing a collaborative educational process. Teacher Nilza (MRR) states that "it is an enriching experience. However, with many challenges. The students progress, even though they need more time than other students".

The teachers agree that there is support from the school management regarding the special educational needs of students with low vision, representing an advance in the school inclusion process. Because when school management participates and supports teachers and students in this process, school inclusion becomes possible:

> my students with low vision are not entitled to a teacher to support school inclusion. Therefore, I need to fill this gap by paying attention to the rest of the class and, at the same time, giving special attention to students with special educational needs. Their notebook is different. I make the lines with a black marker, with a larger space between them and the school reproduces and binds these sheets. The school also buys the 6B pencil to make the writing darker. When I need to use the textbook with the class, the school expands the pages that will be used for the two students with visual impairments. I put them sitting very close to the whiteboard, and I always use the pilot with the darkest colours (black and blue) and make the letter really big. I always read everything with them or for them and the rest of the class. (Teacher Albertina, IC)

Based on the narrative of teacher Albertina, who works in the IC, it is possible to affirm that the school is engaged in making the school inclusion process possible. We also identified teacher Albertina's commitment to supporting students with low vision, not only in the socialisation process but also with regard to "the development of skills and the learning of content necessary for participation in society" (Crochick et al., 2011, p. 213).

However, teacher Albertina's (IC) narrative: "my students with low vision do not have the right to a teacher to support school inclusion", expresses the lack of understanding regarding the role of the teacher of PS for school inclusion, as she considers it necessary a teacher of PS for each student with a disability considered to be in a situation of inclusion. What is lacking is an understanding of the teacher's PS functions for school

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inclusion and optimisation of her participation in the IC, contributing to students' learning process considered to be in a situation of inclusion.

Regarding the question: "do you think there is any kind of relationship and articulation between the democratisation of education and inclusive education? Comment on that", we highlight the following narratives: "yes, if there is no democratisation, relationship and articulation of education and inclusive education, there will be no success in the teaching-learning process. Because one interacts with the other's success" (teacher Bruna, PS);

> I believe that there is a certain relationship and an articulation between the democratisation of education and inclusive education. I think that nowadays, you can't think about education without relating it to inclusive education. We still have many obstacles and barriers to overcome and overcome. However, it has already come a long way. I believe that each day this relationship and articulation, focusing on inclusive education, will gain more strength, seeking greater achievements for students with special educational needs. (Teacher Nilza, MRR)

> I believe so, at least in the Public Network of Niterói, which is the one I know closely. I see, every year, increasing the service to students with special educational needs. At our school, most classes have students in these conditions, with an inclusion support teacher exclusively to accompany them in their socialisation and learning development according to their abilities. (Teacher Albertina, IC)

Thus, we were able to identify that the teachers managed to link the democratisation of education and inclusive education, which can be considered an advance in public policies for inclusive education in the city of Niterói. That said, we affirm that inclusive education provides the participation of all students considered to be in a situation of inclusion.

Final Considerations

After completing this study, we highlight some relevant results: the creation of spaces in the Adelino Magalhães Municipal School for reflection by teachers, managers and the strengthening of inclusive education for all enrolled students with disabilities, considering Crochick et al. (2011), by stating that "equality in the face of the possibility of learning, despite the differences, is a milestone in a democratic society" (p. 214).

With this, education should not be considered a privilege for some students at the expense of many who are outside the public school. But rather as a social and human right, through which students will develop as free-thinking individuals, having access to their own essence — unique and human. Therefore, it can be considered as a central

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result of this study that the Adelino Magalhães Municipal School is significantly affirming inclusive education, especially as a result of the implementation of the public education policies of the municipality of Niterói, which established the school inclusion of students with disabilities as a priority.

The inclusive school is not responsible for selecting students for access to education or differentiating them according to the criterion of disability. Instead, it is up to the school to be a democratic and humane educational space. In this sense, education and access to knowledge become all students' rights. Democratising access to school and giving sustainability to inclusive education is the same as creating spaces for learning and experience between different subjectivities (students, teachers, managers and family members), without hierarchy due to physical, sensory and/or cognitive differences, in the fight against the manifestation of prejudice, the maximum expression of violence against students with disabilities.

Thus, the defence in favour of inclusive education contributes, above all, for students considered to be in a situation of inclusion, in interaction with social limits and other colleagues, without disabilities, in everyday school life to recognise themselves as human beings able to live in society, without fear of the violence of prejudice against their sensory, physical and cognitive differences because they are considered inequality.

Finally, inclusive education needs to be a collective struggle of teachers, administrators and family members who favour public schools. Our fight is for the strengthening and democratisation of access and permanence of students with disabilities and without disabilities, in order for them to live teaching and learning experiences that humanise them and make them capable of experiencing a society that does not recognise differences as the essence of humanity. Inclusive education can drive formation that includes all students, making them sensitive and able to live in society without having their differences denied and/or made invisible by prejudice, the maximum expression of violence against students with disabilities. We hope that this study will contribute to confronting and overcoming segregation in public schools in Brazil.

Translation: Michelli Agra and Valdelúcia Alves da Costa

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References

Adorno, T. W. (1995). *Palavras e sinais: Modelos críticos 2* (M. H. Ruschel, Trans.). Vozes. (Original work published 1969)

Adorno, T. W. (2010). *Educação e emancipação* (W. L. Maar, Trans.). Paz e Terra. (Original work published 1970)

Agra, Michelli. (2015). *Democratização da educação na escola pública: Inclusão de estudantes com deficiência visual* [Master's thesis, Universidade Federal Fluminense].

Alves, D. de O., Alves, M. de O., Dutra, C. P., & Griboski, C. M. (2006). *Sala de recursos multifuncionais: Espaços para atendimento educacional especializado.* Ministério da Educação; Secretaria de Educação Especial.

Costa, V. A. da. (2007). *Os processos de inclusão dos alunos com necessidades educativas especiais: Políticas e sistemas.* Editora UNIRIO.

Crochick, J. L., Freller, C. C., Marian, Á. de L., Feffermann, M., Nascimento, R. B., & Casco, R. (2011). Atitudes de professores em relação à educação inclusiva. In J. L. Crochick (Ed.), *Preconceito e educação inclusiva* (pp. 193–217). SDH/PR.

Decreto nº 7.611, de 17 de novembro de 2011 (2011). http://www.planalto.gov.br/ccivil_03/_Ato2011-2014/2011/Decreto/D7611.htm

Lei Brasileira de Inclusão da Pessoa com Deficiência. Lei nº 13.146, de 6 de julho de 2015 (2015). http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm

Leme, E. S., & Costa, V. A. da. (2016). Educação, inclusão e direitos humanos: Como esse estuário desaguou na escola? *Revista Educação Especial*, *29*(56), 667–680. https://doi.org/10.5902/1984686X10078

Portaria FME nº 878/2009 (2009).

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French Support and Work Assistance Establishment and Social and Professional Integration of Workers With Disabilities in Rural Areas. The Example of Habert (Savoie, France)

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Abstract

This article proposes to address the issue of inclusion through work and in a rural environment of people with mental disabilities and/or intellectual disabilities. Through the example of a French support and work assistance establishment, the support and work assistance establishment Le Habert, located in a small rural and mountainous village in the Alps and offering people with disabilities to work on a farm, the article will first address the importance of work as a means for people to regain their dignity. Between the feeling of usefulness and pride in participating in the operation of one territory, by being fully involved in the process of producing and adding value to a product, accompanying the farm allows, apart from these therapeutic virtues, a real professional inclusion. Living in houses or apartments in the surrounding villages, the accommodation, allowing contact between people with disabilities and local inhabitants is also a vector of social inclusion. However, while the rural setting can be an asset for inclusion because of the professional and social opportunities, the isolation and geographical inaccessibility of the rural mountainous environment can be an obstacle for people who do not necessarily have the means to be mobile. By offering personalised support for mobility, the institution transforms geographical exclusion into an asset for professional, social and spatial inclusion.

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Estabelecimento Francês de Apoio e Assistência ao Trabalho e Integração Social e Profissional dos Trabalhadores com Deficiência nas Zonas Rurais. O Exemplo de Habert (Sabóia, França)

Resumo

Este artigo visa abordar a questão da inclusão através do trabalho e num ambiente rural de pessoas com deficiência psíquica e/ou com deficiência intelectual. Através do exemplo de um estabelecimento de apoio e assistência ao trabalho, o estabelecimento de apoio e assistência ao trabalho Le Habert, localizado numa pequena aldeia rural e montanhosa nos Alpes e que oferece às pessoas com deficiência o trabalho numa quinta, o artigo abordará primeiro a importância do trabalho como meio para as pessoas recuperarem a sua dignidade. Entre o sentimento de utilidade e orgulho em participar no funcionamento de um território, ao estar plenamente envolvido no processo de produção e valorização de um produto, o acompanhamento na quinta permite, para além destas virtudes terapêuticas, uma verdadeira inclusão profissional. Vivendo em casas ou apartamentos nas aldeias circundantes, o alojamento, permitindo o contacto entre pessoas com deficiência e habitantes locais, é também um vector de inclusão social. Contudo, se a ruralidade, devido às oportunidades profissionais e sociais que oferece, pode ser um trunfo para a inclusão, o isolamento e a inacessibilidade geográfica do ambiente rural montanhoso pode ser um obstáculo para as pessoas que não têm necessariamente os meios para serem móveis. Ao oferecer um apoio personalizado à mobilidade, a instituição transforma a exclusão geográfica num bem para a inclusão profissional, social e espacial.

Palavras-chave

França, deficiência, estabelecimento de apoio e assistência ao trabalho, inclusão social e profissional, zona rural

Introduction

Specific structures have been set up in France, the support and work assistance establishment (*Etablissements et services d'aide par le travail*; ESAT; Baret, 2012; Bocquet, 2015; Lajoumard et al., 2019; Zribi, 2012) to promote the social and professional inclusion of people with disabilities. They have the originality of defining a "protected" work framework[1], proposing professional actions and deploying individualised and adapted support (Fourdrignier, 2012; Paul, 2002). At the same time, the ESAT are fully integrated into the economic fabric of the territories they are located in (Baret, 2012). Based on the premise that work is a powerful vector of dignity by allowing each person to express his or her abilities, this article proposes to address different forms of inclusion resulting from medico-social and professional support for people with disabilities in rural areas: inclusion through work and inclusion through housing and mobility. Based on the results of a research action financed within the framework of a call for projects by the Fondation Internationale de la Recherche Appliquée sur le Handicap (FIRAH; International Foundation of Applied Disability Research), associated with Groupe Agrica,

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[1] On the gradual introduction of "protected" work in France, see also Escuriet et al. (2021).

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Laser Emploi and Solidel on the general theme "handicap and rural space", we will focus on the example of the agricultural ESAT of Le Habert, located in Entremont-le-Vieux, in the Savoie region of the Alps, which accompanies people with mental disabilities and/or intellectual disabilities.

We will first focus on the notions of dignity and inclusion to understand to what extent work can enable people with disabilities to conquer the ontological dignity of every human being and find their place in society. Secondly, we will look at the characteristics and particularities of the ESAT Le Habert. Located in the mountains in a rural commune of a little more than 600 inhabitants and managed by an association, it offers, among other things, the possibility for people with mental disabilities and/or intellectual disabilities to work on a dairy farm, to produce cheese and to sell or valorise these products in the commune's inn managed by the establishment. After the presentation of the participative action-research which is based on semi-directive interviews, we will be interested in the therapeutic and inclusive added value of a rural accompaniment, allowing the accompanied persons to conquer their dignity by linking the feeling of freedom conveyed by the mountain, the feeling of usefulness and the pride to participate in the functioning of a territory.

Living in housing in the heart of several villages near the ESAT, we have found that, while allowing a balance between support and autonomy, housing was, in addition to work, a vector of inclusion in its own right. Because of the work opportunities it offers and the social networks it allows to develop, if the rural environment is an asset, the question of managing distance, mobility, and accessibility is a real challenge in this sparsely populated environment. As with work and housing, the various mobility assistance measures offered by the institution, including support for obtaining a driver's license, also act as powerful vectors of autonomy and inclusion.

Theoretical Framework of the Research: Dignity and Professional Inclusion

On December 13, 2006, the United Nations general assembly adopted the Convention on the Rights of Persons with Disabilities. Recalling the principles proclaimed in its charter in the preamble, adopted at the San Francisco conference on October 24, 1945, it insists on all human family members' dignity. Dignity is the key concept of this convention, which aims to promote, protect and ensure "the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and promote respect for their inherent dignity" (Convention on the Rights of Persons With Disabilities, 2006, p. 4).

However, the content of the concept of dignity, which is extremely imprecise, differs according to the discipline that approaches it (law, bioethics, philosophy…). In the original meaning, as relayed by the 1789 Declaration of the Rights of Man and of the Citizen (Déclaration des Droits de l'Homme et du Citoyen, 1789; "all citizens being equal (…) are equally eligible for all dignities, places and public employment, according to their capacity, and without any other distinction than that of their virtues and talents" [Art. 6]), dignity refers to an idea of prestige (Bonjour, 2006). In the 1948 Declaration (Universal

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Declaration of Human Rights, 1948; "all human beings are born free and equal in dignity and rights"), the meaning of the term evolves and expands to qualify what is considered sacred in every human being (Weil, 1949). According to Paul Ricoeur (1988), it "is due to the human being by the mere fact that he is human" (pp. 235–236). This conception of dignity as a common good for all explains why, in the history of philosophical thought, the notion has often been associated with the weakest (Bonjour, 2006): this is evidenced, for example, by the works of Lévinas (1996), Steiner (2005) or even Schopenhauer (1840/1978). The Convention on the Rights of Persons with Disabilities (Convention Relative aux Droits des Personnes Handicapées, 2018) is thus intended to be a first step in reducing the social disadvantage suffered by persons with disabilities, as evidenced by preambular paragraph (y):

> convinced that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage experienced by persons with disabilities and will promote their participation, on the basis of equal opportunity, in all spheres of civil, political, economic, social and cultural life, in both developed and developing countries. (pp. 3–4)

The concept of dignity is broader than the law that frames it. As human beings, people with disabilities have the same rights as so-called "able-bodied" people. Therefore, in principle, they should enjoy the same dignity that is ontological to the human being. However, society does not always recognise this equal dignity of people with disabilities and so-called "able-bodied" people. Thus, an employer will often prefer to recruit an "able-bodied" person for equivalent skills rather than a worker with a disability. Even if many obstacles can explain the difficulties of access to employment for these workers in the mainstream environment (Blanc, 2006), the stigmatisation processes they are likely to undergo should not be overlooked.

Interpreted as a stigma (Goffman, 1963/1975), difference leads to a phenomenon of rejection that keeps people with disabilities away from the world of work. They are not employed because they are considered too different, too fragile, too slow, not capable of doing the work required. This presumed incapacity is transformed into indignity: the person is not considered worthy of accessing the prestige, the consecration which is work. Regardless of the real difficulties of access to employment for workers with disabilities, we note that their dignity is affected in all cases: without work, how can one have one's abilities and usefulness to society recognised? Indeed, if we consider dignity in Boni's (2006) way as the recognition of the human being — of his body, his mind and his abilities —, if we do not recognise and do not allow the professional abilities of these workers to express themselves, how can we give them back their dignity?

In the scientific literature on disability, the link between work, disability, and dignity has been highlighted, particularly by researchers who worked on structuring a social

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model of disability in the 1980s (Filiatrault, 2016). For them, particularly those inspired by materialist and neo-Marxist theories such as Finkelstein (1980), social exclusion, the indignity of belonging to society, is directly linked to the capitalist society that excludes them from the production process. This conception of disability originates in an organisation of society structured around non-disabled people, which has the effect of "creating" disability by leaving no room for different people. The emergence of the social model was the foundation of disability studies and allowed a fundamental paradigm shift in the scientific field and, more generally, how society considers disability. In the 1990s, new research postures on disability inspired by postmodern theories appeared.

Giving less importance to social and material factors and more importance to cultural and ideal factors, postmodern theorists of disability studies focus their analysis on the individual, his culture and his lived experience. For them, disability is not a pathological dysfunction; it is not created by oppressive social structures. Rather, it corresponds to the result of cultural and linguistic construction of a set of norms leading to the sidelining of individuals considered different (Gustavsson, 2004). Although they recognise the usefulness of the social model (Shakespeare & Watson, 2001), they criticise the fact that it focuses almost exclusively on society and its organisation and forgets the individual. They also criticise the social model for "focusing on physical disabilities neglecting other disabilities and health problems such as intellectual disabilities, autism, learning disabilities, deafness and transcapacitism"[2] (Baril, 2013; Filiatrault, 2016, p. 20).

Beyond these theoretical divergences, in addition to insisting on the role of society acting as a real factor preventing people with disabilities from accessing dignity, Ebersold (2009) emphasises that this social conceptualisation of disability, relayed by several texts and international declarations, has participated in the emergence in the public field, but also political and scientific of the concept of inclusion:

> the term "inclusion" is gradually tending to impose itself in the public, scientific or political language in place of that of integration, or even insertion. Inclusion is one of the objectives promoted in 1994 by the Salamanca Declaration, of the rules for the equalisation of opportunities promulgated by the United Nations in the same year, of the Luxembourg Charter promulgated in 1996 by the European Union, and, more recently, one of the indicators retained by the European Union in the framework of the Lisbon Agenda to evaluate public policies (UNESCO, 1994; United Nations, 1994; European Union, 2002). Its consecration is the result of a movement mobilising actors from the associative world and researchers around a social model of disability that refuses to exclude people with a disability in favor of accepting them as different. (p. 71)

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[2] Transcapacitism is characterized for Baril (2013) "by the need, for a person in a non-disabled situation, to transform his or her body in order to be in disabled situations" (p. 144).

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Unlike integration, which assumes that the origin of social inequalities (which integration aims to correct) lies in the intrinsic characteristics of the group being integrated, inclusion repositions the origin of social inequalities in the conditions of access, the obstacles to participation and the barriers existing within the group in which we wish to include another group.

Since they cannot access their dignity because they are excluded from the world of work or victims of stigmatisation, it is no longer a question of inserting people with disabilities but of including them.

Based on the premise that dignity and inclusion require the recognition of the human being, particularly his capacities, the scientific approach that we have set up within the research-action frameworks links the social model of disability and postmodern conceptions. Approaching the subject through the geographical dimension has led us to deploy several scales of analysis. If the individual, his life trajectory, his daily life and his aspirations have constituted the core of our methodological framework, we have not only focused on individual destinies. By constantly bearing in mind that disability is a social construct, the geographical approach enabled us to question the place occupied by these individuals in the society as a whole, in which they try to be included.

Presentation of the Field and Methodology

Le Habert, an Agricultural ESAT in the Middle of the Mountains: Production, Processing and Promotion of Farm Work

Located at an average altitude of 816m above sea level in the heart of the Chartreuse Regional Natural Park, the ESAT Le Habert is located in the commune of Entremont-Le-Vieux (Savoie department), which has 651 inhabitants spread over 26 hamlets. It is a relatively isolated commune: only a secondary road (D912), which crosses the valley, links it to Chambéry, some 20km away (Figure 1).

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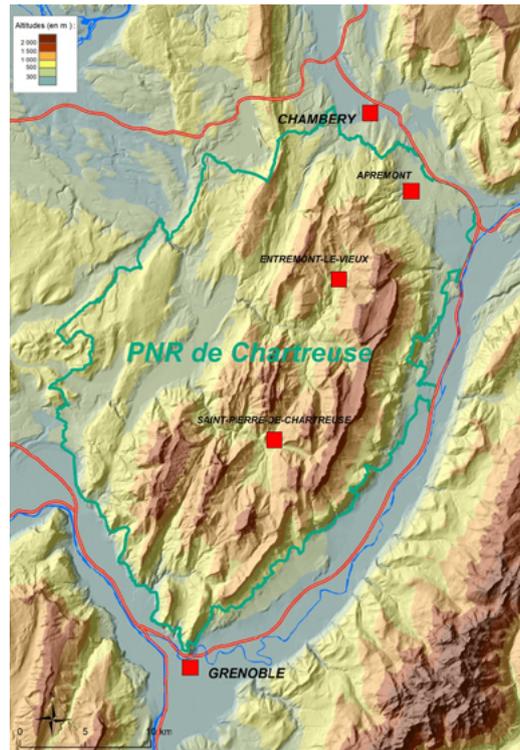
Figure 1 *Location map*

Credits. Eric Langlois

The creation of Le Habert is the result of a reflection by the association Espoir 73[3], which was looking into the question of support and adapted care for people with mental disabilities. The idea of associating medico-social support and agricultural activity emerged from the example of an integration establishment in the neighbouring department. The location of the ESAT Le Habert, in the commune of Entremont, was explained by the presence of three dairy farms that had to cease their activity for lack of a buyer. The creation of Le Habert thus contributed to maintaining agricultural activity in the area (Figure 2).

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[3] Originally, the association was called the National Union of Families and Friends of Sick and/or Psychically Handicapped People (Unafam). Created in 1963, it was later renamed Espoir 73, a departmental association which administers four other specialized establishments.

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Figure 3 *Support and work assistance establishment Le Habert's activity sites: Cheese factory*

Credits. Mauricette Fournier

The association's philosophy is based on the notion of "my life, my choice, my right". Therefore, the support and care provided are based on the psychosocial rehabilitation concept. This concept is based on a global approach to the person, leading to a holistic knowledge of the situation. This concept of psychosocial rehabilitation tends to reinforce the capacities of each person, with the aim of satisfaction and social stabilisation (Bon & Franck, 2018; Boyer, 2011). Thus, the accompanying persons start from the principle that each person has abilities and skills to develop, with respect for the individual, while encouraging him to be an actor of his life.

Today, Le Habert comprises an ESAT with 35 places and one residential home with 29 places. The ESAT accompanies people with psychological disorders and, more specifically, schizophrenia, even if individuals with other disorders can be accommodated. The majority of these people are men, and their age of arrival is between 25 and 35 years old.

The support work is based on agricultural and agri-food activities. First of all, there is the farm where 30 local cows are raised. The milk production is transformed in a cheese-making workshop (production of cheeses, including Bleu de Chartreuse, created by the ESAT, and yoghurts). The products are sold to a local clientele through the ESAT's store (direct sales) and in various valley stores. A part of the products is reserved for the Auberge des Entremonts, the only restaurant in the commune managed by the ESAT. Finally, the workers with disabilities can provide agricultural and/or environmental services (clearing brush, managing green spaces, pruning vines, harvesting grapes, etc.) for local communities or companies (Figure 3).

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Figure 3 *Support and work assistance establishment Le Habert's activity sites: Auberge des Entremonts*

Credits. Mauricette Fournier

Methodology: A Qualitative Approach

Initially, the action research was based on various voluntary interviews conducted with ESAT workers. Following meetings during which the team presented them with the study's objectives, the ESAT workers showed a genuine interest in the study, which was reflected in numerous informal exchanges throughout the fieldwork period and in the number of people who agreed to testify and share their experience. Thus, six workers in the livestock and cheese workshop volunteered to participate in the interviews. They were six men aged between 24 and 58 (four of them were in the 45–55 age group). The interviews took place either at the workplace or during break times. However, before the interviews, time was set aside for discussions to get to know the workers' daily lives and create a link (Table 1).

Categories of actors interviewed	Workforce
Total number of support and work assistance establishment workers	36
Number of workers interviewed	6
Supervisors interviewed	4
Institutional actors interviewed	4
Other civil society actors interviewed	4

Table 1 *Summary table of the actors interviewed*

From a methodological point of view, we cannot ignore the particularity of psychological and mental disabilities in the context of a study based on the words and discourse of the people concerned. Indeed, if mental disability impacts intellectual and learning capacities, communication, socialisation or emotional stability, people suffering from mental disorders are also in a situation of "vulnerability" (Muller, 2011). For the latter, this notion is notably linked to an alteration in their ability to get through a difficult situation, in their relationship with others and with themselves, implying a constantly changing

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emotional stability. Also, to evolve in the real world, the notion of spatiality and physical and social environment (Fougeyrollas & Noreau, 2007) is essential. The emotional state significantly influences the ability to live in society, perform specific tasks, express oneself or evolve within a group (Pachoud et al., 2009). On the other hand, a secure environment favours bonding and exchange.

Therefore, during the interviews, the trust had to be established to facilitate the discussion. Nevertheless, testifying about one's life path and history mobilises emotions. To ensure a friendly atmosphere was maintained, the interviews were adapted to suit the particulars inherent to each participant. That had the effect of causing a loss of information in certain situations, despite the care taken not to censor or over-frame the exchange to encourage the expression of information.

The interviews carried out with the other actors of the territory aimed to contextualise, at various scales, the testimonies of the workers. Discussions with supervisors close to the interviewees (specialist educators and workshop monitors) made it possible to learn about the measures implemented by the establishment to promote the autonomy of Le Habert workers. Meetings with staff from the Maison Départementale des Personnes Handicapées de Savoie, da Communauté de Communes Cœur de Chartreuse, do Parc Naturel Régional de Chartreuse e da Chambre d'Agriculture shed light on the anchoring of ESAT in its territory and the relationships established, at the local as well as the departmental level, with institutional actors (mainly local communities). Finally, a few interviews were conducted with town residents to measure their knowledge of ESAT and their image of the establishment and its workers.

Living in the Mountains, Working in Agriculture: Therapeutic Benefits and Inclusion in the Local Economy and Territory

The research sample has five people from the Auvergne Rhône-Alpes region, including two from the Savoie department. The other person came from the Hauts-de-France region but already lived in the region before entering the facility (Figure 4).

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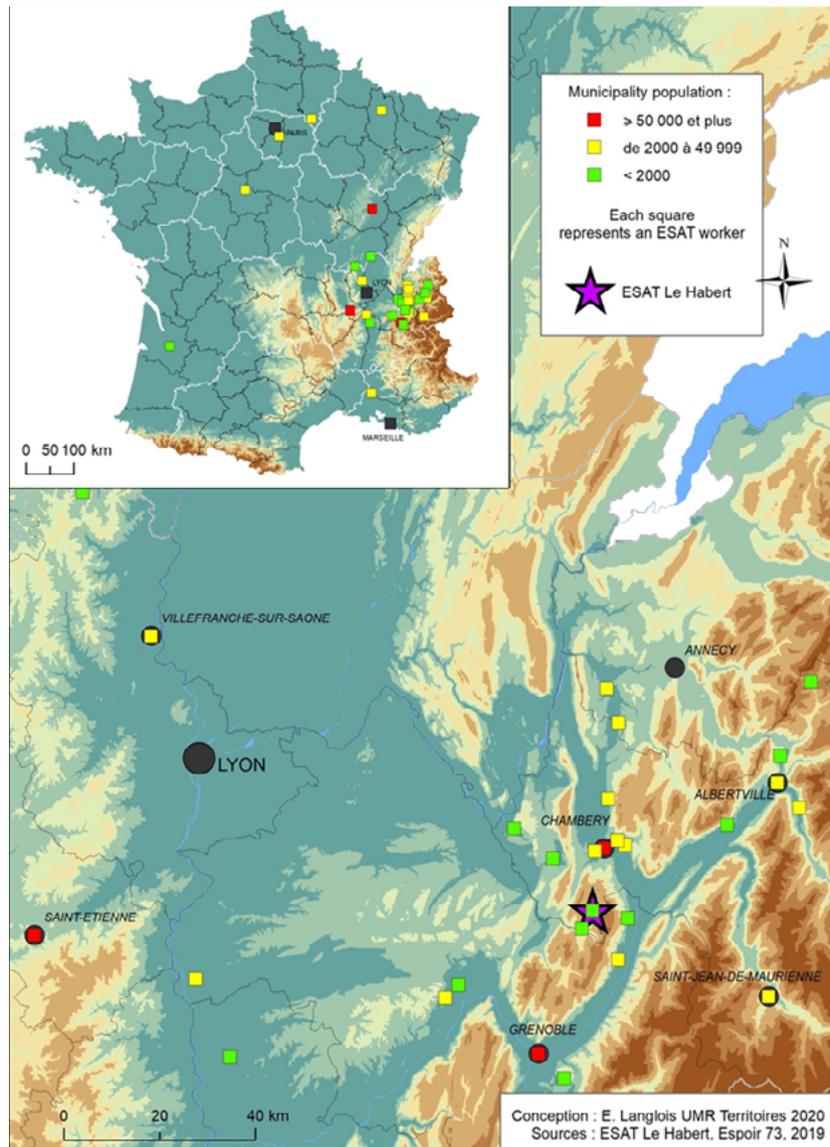
Figure 4 *Origin of the workers at support and work assistance establishment Le Habert*

Note. Each square represents a support and work assistance, establishment worker.

Credits. Eric Langlois

The life courses and the decisions referring to Le Habert, although different, show similarities. Most people have a profile marked by addictions (alcohol, drugs). They have experienced a phase of social breakdown, sometimes involving acts of self-destruction leading to hospitalisations in psychiatry. However, the six interviewed workers chose to come specifically to an agricultural establishment. For three of them, this enthusiasm for the sector can be explained by the fact that they were originally from the area (son of a farmer, former farmer) and the fact that they wanted to return to their roots. "I was born in it (...) I have a job, I like it, I like my tarines[4]" (Pierre[5], worker with disabilities, September 2019).

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[4] The *tarentaise* or *tarine* is a dairy cow originating from the Tarentaise valley in Savoie.

[5] The first names have been changed for the sake of anonymity.

In addition to the well-being of returning to a professional activity, some have highlighted the therapeutic dimension of agricultural work, mainly contact with animals. This example illustrates the powerful vector of dignity that work can represent, reinforcing the self-image.

> Taking care of an animal is going to allow them to project themselves onto themselves, but as a result see themselves in the animal and become aware that you also have to take care of yourself to go well in life. (Jacques, workshop instructor, September 2019).

The therapeutic interest of work, specifically agricultural activity, was also underlined to help people find their bearings and organise their daily lives. Indeed, for people who, because of their disorders, may lack reference points, work allows them to regain a rhythm of life: learning to get up again, organising their day, having a daily goal. Beyond these therapeutic aspects, agricultural work on the farm represents an actual means of inclusion.

Throughout the manufacturing process, the valorisation of the work generates a feeling of social utility and inclusion in the local economy and the territory. By raising, transforming and then valorising the farm's products, the workers have the feeling of being considered as professionals in their own right, with specific know-how. Indeed, working on the farm or in the cheese factory requires organisation, technical skills, and qualities such as patience and organisation.

> There is still a lot of technical knowledge. We have to produce milk in accordance with the cheese market, so we don't let our cows calve in winter. We eat a lot of cheese in the spring, from spring on, in the summer, with all the tourists we have, so we have to have calves at that time. So, you see it's quite technical, and there is a worker who works on it, on the breeding schedule. So, as a result, the reproduction schedule means the quantity of milk. (Cédric, workshop instructor, September 2019)

For the other three, an upstream internship reinforced the interest in ESAT and its environment. Several people questioned thus underlined their interest in the rural environment, the values associated with agricultural work, the feeling of freedom that comes from living in mountain regions or the importance of evolving in an environment mainly protected from multiple temptations: "far from alcohol and drugs" (José, worker with disabilities, September 2019);

> there are the values of the land, (...) there we work on things that are a little ancestral. All those who are here have made the choice to orient themselves towards the rural area. (...) It may be a way for some to rebuild elsewhere, in a quieter place, far from the demands of the city. (Paul, educator, September 2019)

In addition, the ESAT's workshops, especially those related to production and manufacturing, require a certain amount of autonomy from the workers. These tasks

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requiring more autonomy are entrusted to them gradually according to their evolution, which contributes to generating a feeling of self-confidence and a sense of responsibility.

> I didn't trust myself, uh... I had lost my confidence, completely. And then there was a farmer in the valley who got hurt. And my instructor, he called me, he asked me if I wanted to go on secondment, to replace this farmer who had been hurt. So I was always stressed, I didn't have any confidence in myself, and then I found myself all alone on a farm. And so, well, I managed. So I had everything, so I had to milk, uh, prepare the cows, bring the cows in, prepare the cows, milk them, take care of the milk tank, clean the stations, take care of the little calves, and I did that all by myself. And that freed me from a uh, a big weight that I had inside me. (Mathieu, worker with disabilities, September 2019)

Housing and Mobility: A Double Vector of Inclusion

The question of accessibility, defined by Laurent Chapelon (2014) as "the greater or lesser ease with which [a] place can be reached from one or more other places, by one or more individuals likely to travel using all or part of the existing means of transport" (para. 1), has proved crucial in this research, whatever the scale of analysis.

The notion of accessibility in sparsely populated areas first prompts us to question the configurations of the territory. Indeed, the rural environment often implies a relative distance between places, leading to greater difficulty in travelling. Rural areas are also often characterised by the absence of infrastructure (communication routes) or services (public transport) allowing mobility. Richer and Palmier (2012) refer to the potential of a space to be accessible as "territorial accessibility". The rural environment in general, specifically the area where ESAT Le Habert is located, has low territorial accessibility given their spatial configurations (distance, lack of infrastructure and services).

If accessibility depends on the territory's characteristics and on a mobility offer that transcends geographical obstacles, it depends on the actors who wish to move and be mobile. While "accessibility of territories" is a spatial potential, "accessibility of people" is a social potential, which refers to the characteristics of actors, to their "individual or collective capacity to be mobile in space" (Richer & Palmier, 2012, p. 431).

Repositioning the notion of accessibility in rural areas in the context of mental disability leads to questioning the capacity of people to seize the mobility offer and use it to carry out their travels. Indeed, the people accompanied by the ESAT Le Habert and living in a territory with poor accessibility (accessibility of territories) cannot all use a mobility offer to move around (accessibility of people). For example, not all have a driver's license and a vehicle and do not have the same freedom of movement. While some are autonomous in their travel, others, dependent on existing mobility services, sometimes are unable to reach places that are not served by these services independently.

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The concept of motility thus perfectly translates the interaction between accessibility, capacity and autonomy. Proposed by Kaufmann and Jemelin (2004) to describe and analyse the potential of mobility, the notion of motility corresponds to "the way in which an individual or a group makes the field of mobility possibilities their own and uses it to develop projects" (p. 5).

Given their personal problems and the poor intrinsic accessibility of the rural environment, the opening up to work made possible by the ESAT contributes to reinforcing the motility of ESAT workers. Indeed, by helping them acquire a driver's license, the establishment contributes to increasing their "field of possibilities", reducing their dependence on existing services and generally reinforcing their autonomy (Chavaroche, 2014).

More broadly, it increases their capability, their "substantial freedom to achieve different combinations of functioning" (Nussbaum, 2011, p. 39). Conceptualised by Sen (1985), then by Nussbaum (2006, 2011), the notion of capability allows, like motility, but on a broader scale, to express the interaction between a person's abilities and the possibilities offered by his or her environment. An increase in capability expresses increased individual capabilities and increased freedoms or opportunities created by a combination of personal capabilities and a political, social and economic environment. By acting on the environment of people with disabilities and stimulating their capabilities, rural ESAT allow more than simple access to dignity: they give the people who are accompanied by them the possibility to enjoy greater freedom of action and choice.

Independent Living: Social Inclusion Through Housing

The majority of Le Habert's workers live in one of the 13 living units that make up the ESAT's residential home, located in the communes of Entremont-le-Vieux in Savoie (three houses and three apartments) and Saint-Pierre-d'Entremont in Isère (seven apartments). The houses, which accommodate 14 workers, are rented from private owners. Three apartments located in the heart of the village, also rented by simple lease (to a social landlord and the town hall), provide housing for nine workers (two apartments each accommodate four people and one apartment only one person). In addition, the municipality of Saint-Pierre-d'Entremont (Isère) rents six individual apartments to the ESAT du Habert under a social agreement. Finally, the last apartment, rented from a private owner, allows two workers to share a flat in Saint-Pierre d'Entremont.

The accommodation configuration in small living units promotes autonomy and inclusion in the familiar environment. Indeed, the various small units scattered over the territory facilitate integration into society. This configuration encourages the workers to show initiative and autonomy in daily life. They can lead a professional and social life as independently as possible and can access the services and shops of the community and participate in community activities.

However, the workers of the ESAT are scattered over the territory. In the commune of Entremont-le-Vieux reside, 28 people, divided between the town (21 workers), Les Perrets on the outskirts of the commune (five workers) and La Plagne in the direction of

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La Ferme (two workers). In addition, 10 workers live 5 km from the ESAT: two in Saint-Pierre-d'Entremont (Savoie) and six in Saint-Pierre-d'Entremont (Isère). This dispersion of workers raises the question of accessibility and mobility, which appear to be essential, both for daily travel to their place of work and for access to the various shops and services and participation in social life (Table 2).

Résidence	Status	Type of occupancy	Owner	Lease	Number of workers
Auberge 73670 Entremont Le Vieux (apartment)	Support and work assistance establishment (ESAT)	Collective	Mairie	Simple	4
Les Perrets 73670 Entremont Le Vieux (house)	ESAT	Collective	Private	Simple	4
Les Perrets 73670 Entremont Le Vieux	ESAT	Individual	Private	Simple	1
Epernay House 73670 Entremont Le Vieux	ESAT	Collective	Private	Simple	5
Gandy House 73670 Entremont Le Vieux	ESAT	Collective	Private	Simple	5
OPAC/Epernay 73670 Entremont Le Vieux (apartment)	ESAT	Collective	Private	Simple	3
Old town hall 73670 St Pierre D'Entremont (Isère) — six apartments	ESAT	Individual	Townhall	Social	6
Guerre Apartment Le Bourg 73670 St Pierre D'Entremont (Isère)	ESAT	Collective	Private	Simple	2
Epernay 73670 ENTREMONT LE VIEUX	Private park	Individual	Private	Simple	1
Epernay 73670 Entremont Le Vieux	Private park	Individual	Owner	-	1
Epernay 73670 Entremont Le Vieux	Private park	Individual	Private	Simple	1
La Plagne 73670 Entremont Le Vieux	Private park	Individual	Private	Simple	1
La Plagne 73670 Entremont Le Vieux	Private park	Individual	Private	Simple	1
OPAC/Epernay 73670 Entremont Le Vieux	Private park	Individual	Private	Simple	1

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Le Bourg 73760 St Pierre D'Entremont (Savoie)	Private park	Individual	Private	Simple	1
Lot Le Cozon 73670 St Pierre D'Entremont (Savoie)	Private park	Individual	Private	Simple	1

Table 2 *Residential distribution of workers of the support and work assistance establishment Le Habert*

Source. The table was constructed from data collected with the management of support and work assistance establishment Le Habert in 2019.

Getting Around Independently: Spatial Inclusion Through Mobility

Several possibilities are available to the workers to get from their place of residence to the pick-up point, located in Entremont-le-Vieux, where a shuttle system, organised by the ESAT, serves the workshop sites: public transport set up by the Regional Council (Belle Savoie express network), individual hitchhiking or via the Rézo Pouce[6], carpooling. However, these solutions do not meet all the travel needs of ESAT workers (medical appointments in a large city, shopping in certain stores, visits to relatives, outings or vacations outside the region, etc.). Increasing their potential for mobility (motility) necessarily involves strengthening their independence.

When they arrive at Le Habert, most workers do not have (or no longer have) a driving license. Therefore, acquiring a driving license is a priority in the structure's support policy by implementing individualised mobility access projects. The support can take the form of help in preparing for the driving code, contact with driving schools in Chambéry or financial support (up to half the cost of the driving license). That has resulted in an 80% success rate to date within the institution. Thus, four people now have a driver's license in our panel, and three use their own car. The other three continued to hitchhike, carpool, or use public transportation when possible.

> We also encourage them to leave the valley. To go to Chambéry (...) passing the license or that the person is autonomous in their travel (...) some have two wheels, cars without a license because it's the location that generates all this. (André, educator, September 2019)

"Stop, everything (...) on Saturday I manage to go to Chambéry" (Thomas, worker with disabilities, September 2019).

> I'm in the process of getting my license. [Le Habert] doesn't finance, but they reimburse me uh, half of the lessons I will have taken (...) for now, it's walking, farm vehicle, and then the bus when I have to go to driving school and then on Saturday. (Vincent, worker with disabilities, September 2019)

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[6] Rézo pouce is an association and a cooperative society of collective interest.

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There I met C who goes to the pool and who is happy, and there is another gentleman who goes to the pool, and as S has a car, they will perhaps after several sessions like that accompanied, go there both by car. (André, educator, September 2019)

This independence acquired or regained during their stay at the ESAT allows the workers to develop their ability to organise their daily lives and take possession of their living environment. This autonomy also represents a means of accessing professional and social integration more easily (Figure 5).
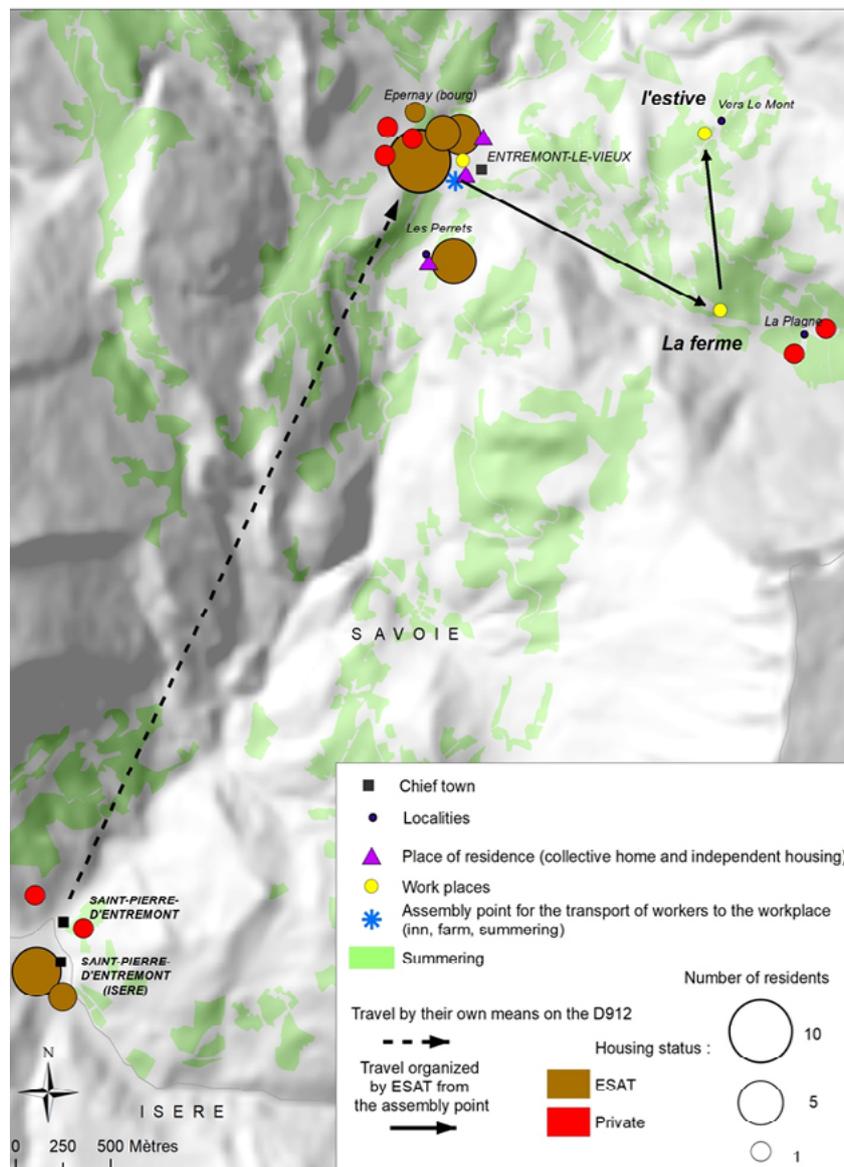
Figure 5 *Workers places of residence and travel to the support and work assistance establishment*

Credits. Eric Langlois

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Conclusion

By enabling people with disabilities excluded from the world of work to engage in professional activity, ESAT's offer them the opportunity to regain their dignity by fully recognising their abilities. Located in a rural mountain environment at an altitude of more than 800 m, the example of the ESAT Le Habert is particularly interesting. The structure offers people with mental disabilities and/or intellectual disabilities inclusion through agricultural work fully rooted in its territory. Having contributed to the maintenance of three dairy farms, the valorisation and transformation of the production carried out by the persons accompanied is generating added value for the territory.

If their work is beneficial for the region (strengthening the economic fabric, maintaining an open landscape), for the clients or people who come to eat at the inn, in return, the ESAT environment constitutes an asset for accompanied workers and their inclusion. Indeed, the example of Le Habert showed that the inclusion of workers in a territory and a system of production, transformation and agricultural valorisation contributed to stimulating self-confidence and generating a strong feeling of social utility. We have also observed that considering the problems of the workers receiving support, the rural environment isolation, the feeling of freedom the mountains provide, the constraints of work and the sense of responsibility it entails all act as a therapeutic tool, contributing to their well-being.

In addition to work, the establishment offers people accommodation in small living units spread out in different villages. That enables them to guarantee real autonomy and inclusion in local social life through accommodation while maintaining the monitoring and support of the ESAT. If the rural environment is an asset for all the elements we have just mentioned, its low population density and the weakness of the collective mobility offer can be, on the contrary, a brake. By helping the workers to obtain their driving license, the institution works towards their autonomy and the reinforcement of their mobility potential (motility). In addition to enabling inclusion through work and housing, the facility ensures spatial inclusion for everyone.

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References

Baret, C. (2012). Les établissements et services d'aide par le travail (ESAT) parviennent-ils à concilier objectifs économiques et missions médico-sociales? Une proposition de matrice stratégique. *RIMHE: Revue Interdisciplinaire Management, Homme & Entreprise, 1*(2), 66–82. https://doi.org/10.3917/rimhe.002.0066

Baril, A. (2013). *La normativité corporelle sous le bistouri: (Re)penser l'intersectionnalité et les solidarités entre les études féministes, trans et sur le handicap à travers la transsexualité et la transcapacité* [Tese de doutoramento, Université d'Ottawa]. uO Research. https://.doi.org/10.20381/ruor-3371

Blanc, A. (2006). Handicap et insertion professionnelle: Égalité et démocratie. *Reliance*, (19), 42–49. https://doi.org/10.3917/reli.019.49

Bocquet, É. (2015). *Les établissements et services d'aide par le travail face à la contrainte budgétaire* (Report No. 409). Sénat. https://www.senat.fr/rap/r14-409/r14-4091.pdf

Bon, L., & Franck, N. (2018). Réhabilitation psychosociale: Outils thérapeutiques et offre de soin. *PSN, 16*(1), 7–16.

Boni, T. (2006). La dignité de la personne humaine: De l'intégrité du corps et de la lutte pour la reconnaissance, *Diogène*, (215), 65–76. https://doi.org/10.3917/dio.215.0065

Bonjour, P. (2006). La dignité humaine, philosophie, droit, politique, économie, médecine: À partir de l'ouvrage coordonné par Thomas De Koninck et Gilbert Larochelle. *Reliance*, (20), 85–92. https://doi.org/10.3917/reli.020.92

Boyer, H. (2011). La réhabilitation psychosociale. *VST - Vie Sociale et Traitements*, (112), 93–96. https://doi.org/10.3917/vst.112.0093

Chapelon, L. (2014). Accessibilité. In *Hypergeo*. https://www.hypergeo.eu/spip.php?article30

Chavaroche, P. (2014). L'autonomie: Paradigme dominant du projet individuel dans le champ du handicap. *Vie Sociale et Traitements*, (122), 72–78. https://doi.org/10.3917/vst.122.0072

Convention on the Rights of Persons With Disabilities, December 13, 2006, https://un.org/disabilities/documents/convention/convoptprot-e.pdf

Convention Relative aux Droits des Personnes Handicapées, July 30, 2018, https://undocs.org/pdf?symbol=fr/CRPD/CSP/2018/5

Déclaration des Droits de l'Homme et du Citoyen, August 4, 1789, http://classes.bnf.fr/laicite/references/Declaration_droits_de_l_homme_citoyen_1789.pdf

Ebersold, S. (2009). Inclusion. *Recherche & Formation*, *61*, 71–83. https://doi.org/10.4000/rechercheformation.522

Escuriet, M., Fournier, M., & Sanson, T. (2021). Les établissements et services d'aide par le travail (ESAT) français face à la pandémie de covid 19: Le rôle du territoire et de la proximité dans l'adaptation à la crise. *Revue Interventions Économiques*, (66). https://doi.org/10.4000/interventionseconomiques.14003

Filiatrault, J.-F. (2016). *Théories sociologiques du handicap: Débats et renouvellement* [Master's thesis, Université du Québec à Montréal]. Archipel. https://archipel.uqam.ca/9158/

Finkelstein, V. (1980). *Attitudes and disabled people: Issues for discussion*. World Rehabilitation Fund. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf

Fougeyrollas, P., & Noreau, L. (2007). L'environnement physique et social: Une composante essentielle à la compréhension du processus de production du handicap. L'exemple des personnes ayant une lésion médullaire. In J. Borioli & R. Laub (Eds.), *Handicap: De la différence à la singularité, enjeux au quotidien* (pp. 47–59). Éditions Médecine et Hygiène.

Fourdrignier, M., & Godard, G. (2012). Interventions. In L'Aire & MéTIS Europe (Eds.), *De la prise en charge à l'accompagnement: Une réflexion éthique sur l'évolution de nos pratiques* (pp. 25–74). Champ Social.

Goffman, E. (1975). *Stigmate: Les usages sociaux des handicaps* (A. Kihm, Trans.). Les Éditions de Minuit. (Original work published 1963)

Gustavsson, A. (2004). The role of theory in disability research – Springboard or strait-jacket? *Scandinavian Journal of Disability Research*, 6(1), 55–70. http://doi.org/10.1080/15017410409512639

Kaufmann, V., & Jemelin, C. (2004, October 21–22). *La motilité, une forme de capital permettant d'éviter les irréversibilités socio-spatiales?* [Conference presentation]. Espaces et Sociétés Aujourd'hui, Rennes, France.

Lajoumard, D., Jagorel, Q., Momboisse, P., Jacquey, B., Laurent, A., & Laidi, C. (2019). *Les établissements et services d'aide par le travail*. Inspection Générale des Affaires Sociales; Inspection Générale des Finances. https://www.igas.gouv.fr/IMG/pdf/2019-026R_ESAT.pdf

Lévinas, E. (1996). *Éthique et infini*. Livre de Poche.

Muller, S. (2011). *Comprendre le handicap psychique: Éléments théoriques, analyses de cas*. Champ Social.

Nussbaum, M. (2006). *Frontiers of justice: Disability, nationalship, species of membership*. Harvard University Press.

Nussbaum, M. (2011). *Creating capabilities: The human development approach*. Harvard University Press.

Pachoud, B., Leplège, A., & Plagnol, A. (2009). La problématique de l'insertion professionnelle des personnes présentant un handicap psychique: Les différentes dimensions à prendre en compte. *Revue Française des Affaires Sociales*, (1), 257–277. https://doi.org/10.3917/rfas.091.0257

Paul, M. (2002). L'accompagnement: Une nébuleuse. *Éducation Permanente*, (153), 4–56.

Richer, C., & Palmier, P. (2012). Mesurer l'accessibilité territoriale par les transports collectifs: Proposition méthodologique appliquée aux pôles d'excellence de Lille métropole. *Cahiers de Géographie du Québec*, 56(158), 427–461. https://doi.org/10.7202/1014554ar

Ricoeur, P. (1988). Pour l'être humain du seul fait qu'il est humain. In J.-F de Raymond (Ed.), *Les enjeux des droits de l'homme* (pp. 233–237). Larousse.

Schopenhauer, A. (1978). *Le fondement de la morale* (A. Burdeau, Trans.). Aubier. (Original work published 1840)

Sen, A. (1985). *Commodities and capabilities*. Oxford University Press.

Shakespeare, T., & Nicholas, W. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9–28. https://doi.org/10.1016/S1479-3547(01)80018-X

Steiner, R. (2005). *Morale et liberté, textes sur l'éthique 1886-1900* (T. Letouzé, Trans.). Triades.

Universal Declaration of Human Rights, December 10, 1948, https://www.un.org/sites/un2.un.org/files/udhr.pdf

Weil, S. (1949). *L'enracinement: Prélude à une déclaration des devoirs envers l'être humain*. Gallimard.

Zribi, G. (2012). L'avenir du travail protégé: Les ESAT dans le dispositif d'emploi des personnes handicapées. Presses de l'EHESP.

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French Support and Work Assistance Establishment and Social and Professional Integration of Workers... · Meddy Escuriet, Mauricette Fournier & Sophie Vuilbert

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Inclusive Education in Contemporaneity in the Light of the Critical Theory of Society

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Abstract

First stated at the end of the last century, the inclusive education proposal had more significant effervescence in the first decade of the current century, as we verified in the scope of the research, studies, and legislative enactments. Nevertheless, the educational process of people with disabilities is precarious in Brazil and worldwide. That is evident both by the unavailability of basic accessibility resources and services and the persistence of beliefs and attitudes that hinder the decent educational inclusion of these people. This article aims to reflect on the educational inclusion of people with disabilities in the contemporary context, taking as a reference the critical theory of society, mainly the studies of Adorno (1970/1995, 1972/2010). It also analyses the need to expand the focus on this issue beyond the specificities of people with disabilities. In parallel, this text points out the need to foster individuals' formation in the educational environment capable of recognizing the humanity within all and each of us. It is considered that this will only be truly possible when the educational systems assume the commitment to the formation of human values that awaken us to perceive similarities and differences in the other as natural aspects of human diversity that constitute us. This change largely depends on proper formation supported by the individuals' critical self-reflection and society, concomitantly. Otherwise, we will be increasingly exposed to barbarism, resulting from a pseudo-formation/semi-formation that still prevails in most institutions.

Keywords

inclusive education, critical theory of society, cultural formation, disability, education

Educação Inclusiva na Contemporaneidade à Luz da Teoria Crítica da Sociedade

Resumo

A proposta de educação inclusiva, iniciada no final do século passado, obteve maior efervescência na primeira década do século vigente, conforme verificamos no âmbito das pesquisas, estudos e promulgações legislativas. Todavia, no Brasil, assim como em muitos países do mundo, o processo educacional de pessoas com deficiência ainda é permeado por muita precariedade, evidenciada tanto pela indisponibilidade de recursos e serviços básicos de acessibilidade, quanto pela manutenção de crenças e atitudes que impedem a inclusão educacional digna dessas pessoas. O presente artigo visa refletir acerca da inclusão educacional das pessoas com deficiência no contexto contemporâneo, tomando como referência a teoria crítica da sociedade, sobretudo os estudos de Adorno (1970/1995, 1972/2010). Analisa-se, também, no decorrer deste trabalho a necessidade de ampliação do olhar em relação a essa temática para além das especificidades que

possuem as pessoas com deficiência. Ademais, buscou-se, paralelamente, apontar a necessidade de fomentar no ambiente educacional uma formação que permita ao indivíduo reconhecer a humanidade contida em todos(as) e em cada um(a). Considera-se que isso só será verdadeiramente possível quando os sistemas educacionais assumirem o compromisso com a formação de valores humanos que nos despertem a perceber nos outros semelhanças e diferenças como aspectos naturais da diversidade humana que nos constitui. Esta mudança depende, em grande medida, de uma verdadeira formação, amparada na autorreflexão crítica dos indivíduos e da sociedade, concomitantemente. Do contrário, ficaremos cada vez mais expostos à barbárie, resultante de uma pseudoformação/semiformação, que ainda impera na maioria das nossas instituições.

Palavras-chave

educação inclusiva, teoria crítica da sociedade, formação cultural, deficiência, educação

Man has always suffered from the lack of eyes on the back of his neck,
and his attitude to knowledge can only be problematic,
because he can never be sure what is behind him;
in other words, he cannot check if the world continues
between the extreme points he manages to see
by stretching out his pupils to right and left. (Calvino, 1991/2007, p. 227)

Introduction

This paper focuses on the educational inclusion of people with disabilities in the light of the critical theory of society (CTS). It is an attempt to expand our view on this issue going beyond the "extreme points", possible to glimpse, even "by stretching out the pupils", like Calvino's (1991/2007, p. 227) metaphor suggests, cited in the epigraph above. At first, reflecting on inclusive education may seem outdated since a lot has been debated on this topic. However, there is an urgent need to deepen this issue when we realise the gap between the numerous inclusivist propositions and the harsh reality of socio-educational exclusion experienced by people with disabilities worldwide, especially in Brazil, where they can barely access the school. Therefore, it is urgent to critically reflect on what we named "inclusive education" from an analytical perspective, based on references that can destabilise the conventional thinking based on the above considerations.

What motivated us to write this bibliographic study was the eagerness to analyse the challenges and the possibilities for the inclusion of people with disabilities in the contemporary socio-educational context. In this sense, we initially approached the possible inclusive education contradictions that reveal challenges to be overcome. And then, we discussed the formation's possibilities as a way to awaken the identification with the human diversity that makes us together, persecuting, whenever possible, a dialectical and reflexive way of thinking.

Contradictions of the Inclusive Education in Contemporaneity

The discussion on educational inclusion has invigorated from the decade of 1990 on, in the last century. It was significantly strengthened in the education area, in human sciences, due to the social movements' pressure to defend the rights of people with disabilities. In this context, some international and national documents of public policies for inclusive education, among which it is worth mentioning in the international context: the World Declaration on Education for All (Declaração Mundial Sobre Educação Para Todos, 1990), the Salamanca Statement (Declaração de Salamanca, 1994), the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (Decreto n° 3.956, 2001), and the International Convention on the Rights of Persons with Disabilities (Decreto n° 6.949, 2009). In Brazil, we emphasised: Law of Lines of Direction and Bases of Education (Lei n° 9.394, 1996), the National Policy for Special Education in the Inclusive Education Perspective (Dutra et al., 2008), and the Brazilian Law of Inclusion (Lei Brasileira de Inclusão da Pessoa com Deficiência, 2015).

We emphasise that the Brazilian legislation has many publications that try to guarantee the rights of people with disabilities. Some of them were rewritten in several ways, such as the one that forbids educational institutions to refuse the enrollment of students with disabilities or global developmental delays. It remains a common practice in many schools, however. When we deeply analyse the Brazilian legislation history on this issue, we observe that the publications follow the trends of the international discourses without necessarily changing the political and social attitude to elaborate such documents.

Many studies and research were conducted addressing educational inclusion and inclusive education as a single concept throughout this time. According to Bueno (2008), "school inclusion refers to a political proposition in action, of incorporating students who have been traditionally excluded from school, whereas Inclusive Education refers to a political goal to be achieved" (p. 49). Replacing nomenclatures to indicate the enrollment of "inclusion students"[1] in traditional educational institutions is not enough. Bueno (2008) emphasises that educational inclusion presupposes enrolling students in the past excluded from school in traditional educational institutions in compliance with the current legislation. On the other hand, inclusive education is a political goal to be achieved in the short, medium, and long term, through numerous actions that favour different forms of learning, ensuring respect for differences, and valuing human diversity.

The differentiation between the two terms can point to a deeper analysis of the issue. However, we consider that establishing a definition is not the most relevant point in this discussion, but the complete understanding that when education[2] is effectively inclu-

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[1] Although the nomenclature "inclusion students" do not exist in the educational legislation valid in school institutions, among teachers and managers this is one of the most frequently used, since "it involves the whole range of students who had as destiny either grade retention or school exclusion due to the low performance presented" (Siqueira, 2008, p. 304).

[2] Education that is not limited to ensuring the enrollment of students in a determined educational institution, but implies, first of all, the access possibility to formation committed to the humanization process, capable of countering the barbarism processes that violate human life. The education/formation conception advocated in this article is anchored in the writings

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sive, it will no longer be necessary to define and/or differentiate it from educational inclusion. Proper education should provide everyone with full development, offering learning alternatives that favour identifying potentialities and overcoming challenges through the formation. Otherwise, we ran the risk of (re)producing a pseudo-formation/semi-formation (Adorno, 1972/2010) by condoning social injustice that biases individuals and/or social groups to prejudice and social discrimination, invariably incompatible with the principles that rule inclusive education.

We use the pseudo-formation/semi-formation concept defined by Adorno (1972/2010) when we state that individuals are being submitted from birth to shape themselves in culture and adapt to society, which merely leads to an adaptation to the cultural environment only. Adorno (1972/2010) argues that "cultural formation now converts into a socialised semi-formation, with the omnipresence of an alienated spirit, which according to its genesis and its meaning, does not precede cultural formation, but succeeds it" (p. 9). He states that "despite all the illustration and information, which is widespread (even with his help), semi-formation prevails in current consciousness" (Adorno, 1972/2010, p. 9).

It is necessary to perceive and announce the challenges inherent to educational inclusion, resulting from the objective social conditions, without failing to bet on its possibilities, especially regarding the posture of radical opposition to the socio-educational exclusion processes that highlight only the individual's special needs to the detriment of the education institutions conditions that hinder and/or prevent formation, replacing it with mere adaptation. As the educational institutions' conditions remain unchanged, barriers to learning, in general, tend to be even more intensified for those students who have been traditionally excluded from school, as long as they do not fit the standards of normality established by culture. This fact constantly raises the emergence of prejudicial behaviour about educational inclusion itself. We reiterate that identifying the difficulties that prevent educational inclusion, among which prejudices, does not mean disagreeing with this proposition. It indicates the need to face what is posed, committing to envision viable alternatives to confront such impediments.

Recognising the barriers regarding educational inclusion may constitute a "first step" to locating the blockages in the individual and, consequently, in the society that makes them opposed to the inclusive experience. Such blockages need to be portrayed because they reveal the existence of a scar that we have to bear. Aware of its causes, we try to resist the risks of new wounds proliferation, especially those (im)posed by the social tissue, due to the experience restriction. In that sense, Adorno (1970/1995) warns us:

> it is needed to recognise the mechanisms that make people able to commit such acts; it is needed to reveal such mechanisms to themselves, trying to prevent them from becoming able to do such acts again, to arouse a general awareness about such mechanisms. (p. 121)

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of Adorno, especially in the work *Education and Emancipation* (1970/1995).

According to CTS assumptions, the mechanisms pointed out by Adorno originated from psychic and social determinations that are interrelated since their genesis. Aware of our predisposition to the mentioned mechanisms, resulting from the contradictions plot inherent to the model of society in which we live, perhaps it is possible to expand our view to envision alternatives that favour starters for a more complete educational inclusion, even considering the challenges that prevent and/or hinder its emergence in the contemporary socio-educational context.

Inclusive Education: The Formation as a Path to Awakening the Identification With Human Diversity That Constitutes Us

Thinking inclusive education is not an easy duty. It assumes a contextualised analysis, as there is no unique perspective of educational inclusion in a country or an educational institution that is universal. Ainscow (2009) states that "different groups in different contexts think of inclusion differently and, again, there is no single, consensual definition" (p. 21). The author summarised some ways to think about inclusion and presented international trends analysis regarding inclusive education within five conceptual perspectives:

1. "Inclusion regarding disability and the need for Special Education: the effectiveness of this approach has been questioned, since, when trying to increase the engagement of students with disabilities, education focuses on the students' disabilities and special needs, and it ignores the other possibilities in which any student participation can be prevented or improved. (...) However, when refusing the idea of inclusion linked to special educational needs, there is the risk of the attention deviation from the ongoing segregation experienced by students with disabilities".

2. "Inclusion as a response to disciplinary exclusions: if inclusion is more commonly associated with children classified as having special educational needs, then in many countries, its connection with bad behaviour is very close. (...) Disciplinary exclusion cannot be understood without being linked to the events and the interactions that precede it, the relationships nature, and the teaching and learning approach in school".

3. "Inclusion concerning all groups vulnerable to exclusion: there is a growing tendency to see exclusion in education more broadly in overcoming discrimination and disadvantage concerning any groups vulnerable to social pressures. (...) Therefore, this broader use of the inclusion and exclusion language is somewhat fluid. It seems to indicate that some common processes link the different forms of exclusion experienced by children with disabilities, children who were excluded from their schools for disciplinary reasons, and people living in poor communities".

4. "Inclusion as a way to foster School for All: it has as its premise the desire to create a unique type of school for everyone that can serve a socially diverse community. However, this emphasis was not followed by an equally strong movement of regular school reform to accept and value the difference. (...) Accepting students, who were considered different, was emphasised within the homogeneity of normality instead of the transformation through diversity".

5. "Inclusion as Education for All: the Education for All (EFA) movement was created in the 1990s around a set of international policies, mainly coordinated by UNESCO, and related to access and the growing participation in education worldwide. (...) In response to the failure of many countries to achieve the goals a decade earlier, the organisers sought to emphasise specific areas in which there may be progress. (...) Despite the apparent progress made to draw attention to the

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possibilities of an inclusive education system for all children, specifically including children with disabilities, this would only happen in the Salamanca Statement in 1994". (Ainscow, 2009, pp. 14–18)

After the publication of the Salamanca Statement[3], some countries outlined some initiatives to transform their policies in the educational inclusion defence (Mittler, 2000/2003). Research and studies, such as those by Ainscow (2009), Mittler (2000/2003), among others, demonstrate that educational inclusion in developing countries is more difficult to achieve. That is because of the lack of institutional and financial support to meet the students' special educational needs in an inclusion situation. There are specific institutional support programs and financial assistance provided by the State to provide such policies in developed countries. However, the proposal for educational inclusion is not always welcomed by those countries: in Spain, a country that hosted the first announcement of this statement, there are many criticisms of the inclusion proposal (Pacheco et al., 2007); as well as in Portugal, where the official legislation supports educational inclusion, but, in parallel, the State also supports the creation of new specialised schools.

Concerning Latin America, Rodriguez (2012) drew an overview of inclusive educational practices, evidencing that, in general, the limits for the implementation of inclusive education in this region — considered one of the world's most unequal — are directly related to the poverty conditions, since:

> undoubtedly, poverty in Latin America is a clear result of the unequal distribution of resources and unequal access to production, but, at the same time, it also generates features that make it more complex and difficult to be resolved. *One of the characteristics of great concern is the loss of social capital, which is reflected in serious social problems such as violence and social insecurity* [empashis added]. The other is State fragmentation, which results in poor planning and disperses and non-effective actions as possibilities to solve the situation. (Rodriguez, 2012, p. 70)

This situation seems to have favoured most Latin American countries, including Brazil, to adhere to the educational inclusion policies proposed by Unesco and other international agencies, in the perspective that the efforts were undertaken to implement these policies leverage changes, at least, to contain the exclusion processes spread through the inclusion discourse.

In Brazil, we verified that in recent decades there had been a sharp increase in the number of students with disabilities enrolled in traditional institutions in all segments of teaching, from kindergarten to higher education, as indicated in the document of the National Policy for Special Education in the Inclusive Education Perspective (Dutra et

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[3] The Salamanca Statement (Declaração de Salamanca, 1994) is considered the most important reference in the development of public policies that aim at educational inclusion in the world and, despite its 27 years of existence, the dream of the inclusive education proposal becomes the "most effective way of fighting discriminatory attitudes, building an inclusive society and reaching education for all" (p. 1), still needs to be fulfilled.

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al., 2008). Most recent data, published by the Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira (2010, 2021) on the 2010 and 2020 school census, reveal that in the last 10 years, the number of students with disabilities and global developmental delays enrolled in regular classes of public schools increased 85%. In 2010 there were 702,603, and in 2020, 1,300,000 students received special[4] education, 92.8% in regular classes.

However, the conditions of access, permanence and course completion for students with disabilities in the Brazilian educational system remain precarious in most educational institutions. Although educational systems allocate resources to implement these policies, the education scenario in Brazil remains precarious, especially about the people with disabilities schooling. We could consider questioning these resources' destinations, as Bueno (2008) pointed out, but this issue deserves a more profound discussion that could be discussed in another study. We consider that the obstacles faced in implementing the educational inclusion proposal in countries such as Brazil may be related, among other issues, to the analysis made by Martins (1997) on the meaning of inclusion policies in exclusion contexts. In the sociologist's understanding, inclusion policies can even, involuntarily, lead the "included" to a "precarious, unstable and marginal inclusion" (Martins, 1997, p. 20) due to the capitalist system maintenance that (re)produces within the educational institutions, such as the case of family, school, university, among others.

The inclusion conceptions categorised by Ainscow (2009) mentioned above were created in diverse international contexts and, as such, present different conceptual perspectives. The author above compared an additional possibility of considering inclusive education in the research conducted in English schools, in 2006, with the collaboration of other scholars in the field. They believe that this proposal should be linked to the "inclusive values related to equality, participation, community, compassion, and respect for diversity, sustainability, and law" (Ainscow, 2009, p. 19).

We share the thinking of inclusive education, but we emphasise that when it comes to the formation, constructing values should start in childhood, as Adorno (1970/1995) suggests. However, an education proposal focused on developing human values from early childhood depends on implementing a collective educational policy taken concomitantly by individuals and society. According to the CTS's assumptions, this policy should be led by managers, teachers, parents, students, administrative employees, and the community, committed to ensuring formation based on experience and critical self-reflection. Otherwise, we run the risk of imposing values in later phases of difficult assimilation for individuals who had been through traumatic experiences, usually resulting from prejudice, which can hinder and/or prevent the possibility of emerging such values.

An education proposal aimed at forming human values implies the possibility of recognising oneself and the other as individuals, invariably belonging to human universal,

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[4] The school census published by Anísio Teixeira National Institute for Educational Studies and Research presented the data of special education students which, according to Article 58 of the Law of Lines of Direction and Bases of the Education (Lei n° 9.394, 1996), are the students with disabilities, global developmental delays, and high abilities or giftedness.

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accomplices of common rights and duties, necessary for a dignified life. In that sense, Silva (2015) remarks:

> Formation from the perspective of inclusive education should enable the people's awareness, in seeing the other as legal subjects whose potential are different, and therefore cannot be seen according to the standards of "normality" or "uniformity" of people's capacities, as if it were possible to format them. (p. 100)

Inclusive education presupposes a formation that enables us, in the development of the socialisation process, the opportunity to differentiate ourselves to realise how diverse we are and, subsequently, to understand that this diversity makes us, dialectically, similar. Thus, Crochick et al. (2013) argue that "identification does not imply being identical, but rather the need for a universal cultural background — incorporated by individuals allowing themselves to express the differences" (p. 21). Therefore, the individuation process is a product of socialisation. We are socialised to differentiate ourselves; it is a process that assumes the achievement of alterity and autonomy. In other terms, as Crochick (2011) highlights, we can state that the individuation process occurs through our ability to differentiate ourselves, as we are encouraged to express our differences and, concomitantly, we learn to accept others' differences. In contrast, culture usually imposes on us a process of idealisation in which we are forced to accept and assimilate patterns normalised by society, in general, inconsistent with socially denied identities. When we are restricted from the possibility of individuation, we learn unconsciously to deny our differences not accepted by culture and/or civilisation because we "socialised in tow", unable to differentiate ourselves, to recognise who we really are. Consequently, we cannot bear to recognise the difference in the other because it reminds us of our subalternity in the face of objective social conditions.

To what extent is it possible to glimpse inclusive education from the perspective of the values defined by Ainscow (2009) in social contexts that hinder and/or prevent the individuation process? The individuation, that is, the individual differentiation process that leads us to identify with "one of the similar", is a fundamental condition of our human nature. Because, "even before being individual, man is one of the peers, he relates to others before explicitly referring to the self; it is a moment in the relationships in which one lives before he can finally reach self-determination" (Horkheimer & Adorno, 1956/1973, p. 47).

Therefore, the identification resulting from the individuation process makes us capable of differentiating and, dialectically, empowers us to embrace the numerous manifestations of differences inherent to human diversity that also constitutes us. Therefore, we became naturally predisposed to include, insofar as we identify ourselves with the other. Identification, as Crochick (2011) states, "can be defined as the search for the

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universal, in particular, its denial is concerned with this universal: the other is not recognised in its humanity" (p. 37). Hence, it is impossible to consider the educational inclusion of the other, not recognised in his humanity as one of us — in the "pain and the delight of being what one is"[5] and/or who one is. In order to be included, it is necessary self-recognition, and, also, to be recognised by the human universal who makes us an integral part of human diversity, regardless of our differences and/or particularities of social, economic, cultural, physical, cognitive, sensorial, ethnic, religious, among others.

In this way, for inclusive education to be actually effective, the identification between individuals must happen based on the certainty that all men and women belong to human universal, capable of incorporating each particular (different) as an indispensable part of human diversity. Otherwise, Ainscow (2009) suggests that the inclusive values no longer apply, as they tend to succumb to the pitfalls imposed by non-inclusive socialisation processes, which we are subjected to constantly.

It is noteworthy that the problem of educational inclusion exceeds the propositions of public documents and policies. We assume that it is linked to the living and survival conditions of students and educators and the population as a whole. However, the relevance of public policies to leverage the possibilities and highlight the challenges of inclusive education cannot be underestimated. It is proved when we take as a parameter the analysis and critical reflection of the impact of these policies in progress in the different educational contexts. Hence we need to consider inclusion from a framework that allows us to understand the contradictions listed in this reflection.

When cultural formation does not allow our individuation and imposes forced socialisation based on the capitalist modes of production, identification tends to be denied and/or replaced by idealisation. In identification, idealisation can emerge when we face something or someone unknown/different, but, as we have the opportunity to experience what causes us strangeness, idealisation can be metamorphosed into identification. We discovered the same human metaphor in other species: caterpillars turn into butterflies in their cocoons, but we need to recognise the transcendence power of the caterpillar in the cocoon.

The socialisation process tends to be favoured through the individuation process that is possible due to the possibility of individual differentiation in society. Given the opportunity to perceive oneself as different and to have the differences welcomed, it is latent in the individual's need to accept the difference in the other. In contrast, when individuation is previously denied in the mass socialisation process, the possibilities of welcoming the difference of oneself and the other are aborted since models are always imposed to "clone a butterfly", taking the metaphor mentioned. Instead of recognising the butterfly's latent presence in the caterpillar, mass culture undermines and devalues the "caterpillar" expression possibilities represented by human diversity. Thereby, the

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[5] Expression used by Caetano Veloso in the song "O Dom de Iludir" (The Gift of Illusion; 1986).

butterfly condition is idealised, denying the transcendence represented by the cocoon inherent to the species. One needs to understand, to break with this cycle that culminates in the social denial of difference, as pointed out by Crochick (2011), that "in each particular, the difference enunciates another possibility of being, which strengthens individuation and society" (p. 34).

In general, identification is not encouraged in our formation, but it is vehemently denied, in the family, school, university, religious orders, workplace, media, or other institutions responsible for our cultural formation. We deny ourselves by denying identification with the other since we belong to human diversity. The difference is our main feature, regardless of our choices and/or particularities. Thus, "this denial is illusory, because clearly what is human can be recognised in all people; anyone who denies identification has to force the ignorance that something in himself is common to the other and vice versa" (Crochick, 2011, p. 37). Perceiving and identifying the processes that can lead us to deny the presence of the other in us is of fundamental importance to avoid strengthening a cultural formation unfavourable to inclusive values development.

As already mentioned, the possibility of critically reflecting on oneself and the other should be encouraged in our formation since early childhood. However, for this to happen, it is necessary to think about the meanings of our own formation in contemporaneity: How does our formation interfere with the constitution of our values? To what extent is our formation committed to the "emancipation of men"[6]? How are social inequalities justified in societies that produced enough knowledge and technologies to overcome them? What is the role of a formation that coexists with social injustice and, in parallel, does not admit the differences manifestation so relevant to human diversity? How can we foster the development of human values' development in a society in which suffering and death are banalised every day?

These questions are consistent with what was already advocated by Adorno (1970/1995) when he highlighted the coexistence inconsistency of so many technological and scientific advances with an increase in the same intensity of social inequalities. Adorno (1970/1995) indicates the need to focus the educational objectives on making us human,

> being in the civilisation of the highest technological development, people find themselves held back in a peculiarly uneven way regarding their

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[6] In the song "Queremos Saber" (We Want to Know), a composed by Gilberto Gil in 1976 and interpreted by Cássia Eller, in the *Acústico MTV* album (2001), we face a poetic reflection on the supposed relationship between knowledge and human emancipation, as the lyrics suggest: "we want to know what will be of the new inventions. We want some more serious news about the discovery of antimatter and its implications in men's emancipation from huge populations. Poor men from the cities, from the steppes, of the outbacks. We want to know when we will have a cheaper laser ray. We actually want a report, a more serious picture of the mystery of light, the light of the flying saucer, for the enlightenment of the men, so needy and in suffering. So lost in the distance from where the Lord's lives. We want to know, we want to live confidently in the future. That is why it is necessary to predict the itinerary of an illusion. The illusion of power, because mankind was allowed to know so many things. It is better that everyone knows what could happen. We want to know, we want to know, we all want to know" (Gil, 1976).

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> own civilisation - and not just because they have not experienced, in their overwhelming majority, the formation in the terms corresponding to the concept of civilisation, but also because they were taken by primitive aggressiveness, a primitive hatred, or, in cultured terminology, an impulse of destruction, which contributes to further increase the danger that this whole civilisation has come to explode, in fact, an immanent trend that characterises it. I consider it so urgent to prevent this that I would reorder all the other educational objects for this priority. (p. 155)

In order to permanently encourage human values development based on social justice, solidarity, the culture of peace, cooperation, and ethics, formation urgently needs to oppose the social model that produces it. These questions reveal how we are far from a correct formation and, simultaneously, they denounce the urgent need for a formation that stimulates us to call into question and, mainly, to outrage us in the face of the precarious living conditions that hinder and/or prevent our individuation and, consequently, makes inclusive education unfeasible. Again, in the words of Adorno (1972/2010), "the only possibility of survival that remains to culture is the critical self-reflection on the semi-formation, in which it was necessarily converted" (p. 39).

In Brazil, the proposal for inclusive education seems to glimpse these values. At least in the public policy documents, expressed in the National Policy of Special Education from the Perspective of Inclusive Education (Dutra et al., 2008), which defines inclusive education as an

> educational paradigm based on the concept of human rights, which combines equality and difference as inseparable values, and which advances in relation to the idea of formal equity by contextualising the historical circumstances of the production of exclusion inside and outside the school. (p. 5)

In the international scenario, Ainscow (2009) demonstrated, through research, the meanings of the inclusive values and its implications for inclusive education to be conceived as:

> a process of transforming values into action, resulting in educational practices and services, in systems and structures that embody such values. We can specify some of them because they are an integral part of our inclusion concept; others we can identify with a reasonable degree of certainty, based on what we learned from experiences. That means that inclusion can only be fully understood when its fundamental values are exhaustively clarified in particular contexts. (p. 21)

The transformation of values into action suggested by Ainscow (2009) seems to be linked to the proper formation, which, according to Adorno (1970/1995), must be based

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on experience and critical self-reflection. The lack of self-reflection would make every inclusive education proposal run the risk of being aborted since its beginning, especially in the contemporary context. The denial of human and/or inclusive values results from a precarious formation, marked by the absence of experience and critical self-reflection that contributes to the spread of prejudice and social discrimination. When prevented from the individuation process that would allow us to recognise and express our differences, we tend not to accept the differences of others because we become unable to establish identifications, especially with those who have differences relevant to human diversity, socially underestimated due to the idealisation processes established by our cultural formation. In this sense, Adorno (1970/1995) warns us: "it is necessary to counteract such a lack of awareness, it is necessary to avoid people striking to the sides without reflecting about themselves" (p. 121).

It is worth noting that the inclusive values cited by Ainscow (2009) are similar to the values defended in the Universal Declaration of Human Rights (Declaração Universal dos Direitos Humanos, 1948), which must be incorporated by everyone, regardless of any specific educational proposition. On the one hand, perhaps the "inclusive" education qualifier is just a redundancy to remind us of how we are moving away from our human nature due to the impossibility of having experience and reflecting on oneself and the other. On the other hand, reaffirming the need to exercise these values is also another way of expressing our desire for a more dignified life and denouncing our hunger for social justice.

In this sense, Crochick et al. (2020) argue that truly inclusive education will only be possible when the discussions on human rights and public policies manage that the struggle for a democratic society could be mediated by the experience and the awareness process of an emancipating human education. That way, it would be capable of pointing out the contradictions the society keeps reinforcing. In the respective authors' opinion, any form of inclusion, especially the educational, will only be possible when we overcome the contradictions inherent to a violent society. We must enhance the arguments used to defend a constant review and update of the inclusive education proposals and keep the efforts to grant individuals a reflexive formation, to face a still undemocratic society, contradictory, about the understanding and acceptance of diversity as part of us.

Conclusions

In conclusion, we can infer that the possibility of building human values and/or "inclusive values" (Ainscow, 2009) depends mainly on the possibility of perceiving our differences through the individuation process and, consequently, establishing identifications with our fellow beings, especially with those considered more fragile, because this is the only way we aroused to recognise our own fragility, inherent to human nature.

The conquering of a fully inclusive education requires the permanent struggle for a cultural and educational formation capable of countering, as much as possible, the

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psychic and social determinations that prevent and/or limit the manifestation of the differences present in human diversity. Otherwise, we will be condemned to fall into the plot of idealised inclusion that insists on threatening the possibilities of the existence of naturally inclusive human values.

Finally, it is worth emphasising that thinking of inclusive education requires the recognition of the contradictions inherent to such a proposal, considering our model of society that still insists on dehumanising us, even in the face of the achievements of legal rights and a pandemic scenario revealing the natural vulnerability to humans. However, it is necessary to seek the experience footprints in the contemporary cultural formation, even considering its limits, because the problem of educational inclusion exceeds the scope of education in the formal sense of the word.

It is urgent to reflect on a society model that maintains inequalities to strengthen and/or "trading" places to be achieved in a power hierarchy. Thus, we understand that in contemporaneity, the individuation and socialisation processes are related and, for that, our educational practices need to highlight the contradictions present in the current attempt at social inclusion to promote a cultural formation. The formation needs to make people capable of countering this adaptation that does not question the status quo and cannot resist everything that prevents us from identifying ourselves with the fragility inherent to our species and from realising how much specificity exists in human universal.

Translation: Shirlei Tiara de S. Moreira

References

Adorno, T. W. (1995). *Educação e emancipação* (W. L. Maar, Trans.). Paz e Terra. (Original work published 1970)

Adorno, T. W. (2010). Teoria da semiformação (N. Ramos-de-Oliveira, Trans.). In B. Pucci, A. A. S. Zuin, & L. A. C. N. Lastória (Eds.), *Teoria crítica e inconformismo: Novas perspectivas de pesquisa* (pp. 8–44). Autores Associados. (Original work published 1972)

Ainscow, M. (2009). Tornar a educação inclusiva: Como esta tarefa deve ser conceituda? In O. Fávero, F. Windyz, T. Ireland, & D. Barreiros (Eds.), *Tornar a educação inclusiva* (pp. 11–23). UNESCO.

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Inclusive Education in Contemporaneity in the Light of the Critical Theory of Society · Jaciete Barbosa dos Santos & Jenifer Satie Vaz Ogasawara

Bueno, J. G. S. (2008). As políticas de inclusão escolar: Uma prerrogativa da educação especial? In J. G. S. Bueno, G. M. L Mendes, & R. A. dos Santos (Eds.), *Deficiência e escolarização: Novas perspectivas de análises* (pp. 43–63). Junqueira&Marin.

Calvino, I. (2007). *Por que ler os clássicos* (N. Moulin, Trans.). Companhia das Letras. (Original work published 1991)

Crochick, J. L. (2011). Preconceito e inclusão. *WebMosaica Magazine*, *3*(1), 32–42. https://seer.ufrgs.br/webmosaica/article/view/22359

Crochick, J. L., Costa, V. A., & Faria, D. F. (2020). Contradições e limites das políticas públicas de educação inclusiva no Brasil. *Educação: Teoria e Prática*, *30*(63). https://doi.org/10.18675/1981-8106.v30.n.63.s14628

Crochick, J. L. Kohatsu, L. N., Dias, M. A. L., Freller, C. C., & Casco, R. (2013). *Inclusão e discriminação na educação escolar*. Alínea.

Declaração de Salamanca: Sobre Princípios, Políticas e Práticas na Área das Necessidades Educativas Especiais, June 10, 1994, http://portal.mec.gov.br/seesp/arquivos/pdf/salamanca.pdf

Declaração Mundial Sobre Educação Para Todos, March 5–9, 1990, https://www.unicef.org/brazil/declaracao-mundial-sobre-educacao-para-todos-conferencia-de-jomtien-1990

Declaração Universal dos Direitos Humanos, December 10, 1948, https://unesdoc.unesco.org/ark:/48223/pf0000139423

Decreto nº 6.949, de 25 de agosto de 2009 (2009). http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2009/decreto/d6949.htm

Decreto nº 3.956, de 8 de outubro de 2001 (2001). http://www.planalto.gov.br/ccivil_03/decreto/2001/d3956.htm

Dutra, C. P., Griboski, C. M., Alves, D. de O., & Barbosa, K. A. M. (2008). *Política nacional de educação especial na perspectiva da educação inclusiva*. http://portal.mec.gov.br/arquivos/pdf/politicaeducespecial.pdf

Gil, G. (1976). Queremos saber [Song]. In *O viramundo, vol 2*. PolyGram.

Horkheimer, M., & Adorno, T. W. (1973). *Temas básicos da sociologia* (Á. Cabral, Trans.). Cultrix. (Original work published 1956)

Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira. (2010). *Censo escolar 2010: Visão geral dos principais resultados*. Ministério da Educação. https://download.inep.gov.br/download/censo/2010/apresentacao_divulgacao_censo_2010.pdf

Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira. (2021). *Censo da educação básica 2020: Resumo técnico*. Ministério da Educação. https://download.inep.gov.br/publicacoes/institucionais/estatisticas_e_indicadores/resumo_tecnico_censo_escolar_2020.pdf

Lei Brasileira de Inclusão da Pessoa com Deficiência. Lei nº 13.146, de 6 de julho de 2015 (2015). http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm

Lei nº 9.394, de 20 de dezembro de 1996 (1996). http://www.planalto.gov.br/ccivil_03/leis/l9394.htm

Martins, J. de S. (1997). *Exclusão social e a nova desigualdade*. Paulus.

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Mittler, P. (2003). *Educação inclusiva: Contextos sociais* (W. B. Ferreira, Trans.). Artmed. (Original work published 2000)

Pacheco, J., Eggertsdóttir, R., & Marinósson, G. L. (2007). *Caminhos para a inclusão: Um guia para o aprimoramento da equipe docente.* Artmed.

Rodríguez, L. M. (2012). El panorama latino-americano de las prácticas inclusivas. In Z. J. Cúpich, S. L. V. López, & L. M. Rodríguez (Eds.), *Sujeto, educación especial e integración* (Vol. VIII, pp. 67–91). Universidad Estatal a Distancia de Costa Rica; Universidad Nacional Autónoma de México.

Silva, A. M. M. (2015). A formação docente na perspectiva da educação inclusiva e a relação com os direitos humanos. In V. A. da Costa & A. M. M. Silva (Eds.), *Educação inclusiva e direitos humanos: Perspectivas contemporâneas* (pp. 91–116). Cortez Editora.

Siqueira, B. A. (2008). Inclusão de crianças deficientes mentais no ensino regular: Limites e possibilidades de participação em sala de aula. In J. G. S. Bueno, G. M. L. Mendes, & R. A. dos Santos, (Eds.). *Deficiência e escolarização*: *Novas perspectivas de análises* (pp. 301–347). Junqueira&Marin.

Veloso, C. (1986). Dom de iludir [Song]. In *Totalmente demais*. PolyGram.

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Professional Inclusion of Down Syndrome Workers in the City of São Paulo: Personal Achievement, Productivity, and Social Relationships in the Work Environment

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Abstract

The objective of this article is to present a debate about data collected within the scope of the research *Professional Inclusion of Workers With Down Syndrome in the City of São Paulo* developed at the Laboratory of Studies on Prejudice located at the Psychology Institute at the University of São Paulo. The survey, held in 2017, aimed to understand different dimensions regarding 20 young people with Down syndrome being included in the working world. Based on the data collected through observations and semi-structured interviews with young people, co-workers, managers, family and friends, the research analysed aspects related to personal achievement, productivity, and social relationships that occurred in the workplace. Despite the general trend towards precarious working conditions affecting a significant part of the Brazilian population, young people showed satisfaction with their work activities. They proved productivity compatible with the activities they were required to perform and maintained good social relationships with colleagues, managers, and clients in the companies they worked.

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Inclusão Profissional de Trabalhadores com Síndrome de Down na Cidade de São Paulo: Satisfação Pessoal, Produtividade e Relações Sociais no Ambiente de Trabalho

Resumo

O presente artigo objetiva apresentar as discussões acerca dos dados coligidos no âmbito da pesquisa *Inclusão Profissional de Trabalhadores com Deficiência Intelectual na Cidade de São Paulo* desenvolvida no Laboratório de Estudos sobre o Preconceito, sediado no Instituto de Psicologia da Universidade de São Paulo. A pesquisa, realizada em 2017, objetivou compreender diferentes dimensões referentes à situação de inclusão de 20 jovens com síndrome de Down no mundo laboral. A partir de dados coligidos mediante a realização de observações e entrevistas semiestruturadas junto dos jovens, colegas de trabalho, chefias, familiares e amigos, a pesquisa analisou aspectos concernentes à satisfação pessoal, à produtividade e às relações sociais que se dão no ambiente de trabalho. De modo geral, mesmo diante da tendência generalizada de precarização das condições de trabalho de grande parte da população brasileira, os jovens demonstram satisfação com as atividades laborais, apresentaram produtividade compatível com relação às atividades a eles requeridas e mantiveram boas relações sociais com os seus colegas, chefias e clientes das empresas em que trabalhavam.

Palavras-chave

inclusão profissional, teoria crítica da sociedade, trabalhadores com síndrome de Down, preconceito

Introduction

The reviews about changes within the work scope, mainly during 19th and 20th centuries, aim at significant moves towards personal empowerment possibilities in the face of the entire social organisation. The transition from material production, based on small family businesses, to an organisation based on the progressive rationalisation with technological base, which allowed greater exploitation of the productive forces and the expansion of the capitalist mode of production, ended up obliterating the possibilities of expression of individual freedom in the face of powerful mechanisms of control and administration of collective life that characterise the current mode of production. Due to the self-preservation need, people need to integrate themselves — through intense socialisation processes at different institutions, since early childhood, to the domination rationale (Horkheimer & Adorno, 1947/1985). The contemporaneous industrial civilisation reduces human life capabilities to the income principle, demanding people vital energy to the status quo maintenance, which ensures the production and the capitalist reproduction. The technological rationale that describes the world of work overruns all human relationships, from family entities to educational ones and all social stages. According to Marcuse (1964/1979):

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> the government of developed and developing industrial societies can only
> be kept and guaranteed when it successfully assembles, organises, and
> exploits the technical, scientific and mechanical productivity available to
> industrial civilisation. And this productivity gathers the society, above and
> beyond any person or group interests. (p. 25)

Under these conditions, people should try hard to adapt themselves to the social order to ensure the material grounds needed to make their living possible. Group and personal interests are consumed by the workforce technological rationalisation. The basic needs of feeding, housing, clothing, and social group sense of belonging are monitored by a rationale that does not refer to these needs fulfilment, ultimately, but for keeping the domination devices and life administration. Through intense training processes, people, due to the pressure for social order adaptation, are forced to identify themselves with the immediate and automatic means of production. The social order's repressive character implies a great control over the individual and the group vital energy and ends up by framing false needs production that prevent the capacity for awareness of the faced oppressiveness. According to Marcuse (1964/1979):

> we can distinguish the real needs from the false ones. The "false" ones are
> those over imposed to the person by peculiar social interests when restraining him: the needs which immortalise the hard daily work, the aggressiveness, the misery and the injustice. (p. 26)

Due to the current civilisation stage accrued material, the expended energies towards the labour — the meaningless work — could be mobilised to fulfil the true needs and no longer those which detach individuals from their sole satisfaction of their potentialities, the possibility of human life happiness realisation.

Marcuse (1955/1968) calls attention to the destructiveness as opposed to "the awareness that (people) could work less and define their own needs and pleasures" (p. 93). This destructiveness contains the irrationality in the workforce, which does not accomplish the current time possible capabilities, even in the face of technological advance, but also in the evaluation provided by a "false awareness" about these social determinations. When questioned about his own happiness, the person answers according to his integration with the whole, although a damaged whole. The satisfaction evaluation shifts and changes the happiness contents. According to Marcuse (1955/1968):

> the principle expresses a condition more than peculiar, more than subjective; happiness is not on the pure sense of achievement, but on the concrete situation of freedom and achievement. Happiness concerns of knowledge: it is a privilege of the *animal rationale*. With the awareness decline, with the information control, and the individual's absorption by the mass communication, knowledge is managed and conditioned. (p. 96)

The theorist understands that happiness needs knowledge and pleasure for the concrete realisation of freedom. However, freedom and knowledge find difficulties in our society due to alienated work. To Marcuse (1964/1979): "the person who is alienated gets drowned by his alienated existence" (p. 31). Marcuse shares the Marxian view to distinguish labour and toil. The alienated work, on which the relationship with the object is lost, forbids knowledge and freedom. The alienation principle has become doubtful to Marcuse due to the individuals' tendency to identify with the existence they imposed on themselves (Marcuse, 1964/1979). However, like Marx, the author understands that awareness arises from the subject-object relationship and the possibility of understanding and anticipating the attaintment of a free society. The revolution or workers' fight for a decent life is possible at each glimpse of freedom and dignity present in the objects of social life.

Would it be possible to be happy and pleased with the work nowadays? According to Marcuse's comprehension (1964/1979), one can be happy if he gets to know and achieve freedom specifically. This achievement, however, cannot be possible in the face of the domination imposed by the managed life. Nonetheless, the author explains that: "the more rational, productive, technical, and total the repressive of society management becomes, the more unimaginable are the ways and means by which managed individuals can break out of their servitude and gain their own release" (Marcuse, 1964/1979, p. 28).

If the possibility of breaking down with servitude seems to be a glimpse in the middle of a managed life, we need to understand the moments in which the workers may foresee knowledge and freedom. In the case of this study, it is necessary to understand some aspects of the situation of including workers with Down syndrome in the world of managed work.

The Situation of Workers With Mental Disabilities in Brazil

In Brazil, during the 90s, some laws were published concerning the right of people with mental disabilities to work positions. The Law No. 8.213/1991 (Lei n° 8.213/1991, 1991) granted the right to work to people with mental disabilities, deploying plans and benefits from Social Security. Article 89 of this law states that it is Social Security responsibility to provide "qualification and social rehabilitation" to a person with mental disabilities, as well as a beneficiary partially or totally disabled, being responsible for providing to these beneficiaries "the means of professional (re)education and (re)adaptation aiming to join the market labour and the country situation in which they live" (Lei n° 8.213/1991, 1991). In Article 93, the law imposes a percentage of workers with disabilities within the total number of employees in a company.

If "the exclusion always brings a specific organisation of interpersonal or intergroup relationships, in a material or symbolic way" (Jodelet, 1999, p. 53), so we can understand that the quoted law aims to organise these relationships, mainly towards the work of people with disabilities. In the organisation of work, we must pay close attention when the exclusion becomes:

> in the case of segregation, through a leave, of keeping a topological dis-
> tance; in the case of a marginalisation by keeping an individual away from a
> group, an institution, or a society; in the case of discrimination, through the
> access closing to some assets or resources, some papers or status or even
> through a differential or negative closing. (Jodelet, 1999, p. 53)

Considering this concept provided by Jodelet (1999), Crochick et al. (2013) devel-
oped research inspired by frankfurt studies (Adorno, 1950/2019), on which segregation,
marginalisation, and discrimination were analysed as prejudice expressions in the con-
text of inclusive education. Similarly, the professional inclusion of workers with mental
disabilities is understood as a necessary political action to overcome topological seg-
regation in the workplace, the marginalisation that sets workers apart from labour rela-
tions, and the discrimination which refutes equality at work.

Costa et al. (2011) appreciate the labour activity by people with mental disabilities
as part of social inclusion. They present a recurring excuse provided by companies for
not hiring people with mental disabilities for having professional skills. Still, according
to these authors, in answer to the request for more qualification, professional training
workshops for work in specialised institutions can provide greater autonomy for future
workers; however, they also suggest that these workshops may indicate that people with
mental disabilities would not be "ready" for adult life.

Regarding the conditions of inclusion of a person with Down syndrome in the la-
bour market, Zarur and Domingues (2017) declare that:

> Down syndrome is related to learning difficulties, meaning that the employ-
> ees with trisomy will probably take longer to perform some activities. That
> does not mean that these tasks will not be done or will be done wrongly.
> Thus, it is always important to follow up this person's adaptation to work to
> determine, together with this employee, which will be his/her responsibili-
> ties and activities to be developed. (p. 34)

However, it is necessary to question if this "learning difficulty" would not be as-
sociated with negative social representations towards Down syndrome, mainly at the
workplace. On the other hand, it is common sense that all workers need the training to
perform their work tasks.

It is necessary to consider that the number of hiring people with mental disabilities
is low compared to other disabilities and, when they occur, the open jobs are opera-
tional, performing simple tasks and with low compensation (Lorenzo & Silva, 2007).
Simonelli and Camarotto (2011) suggest an inclusive model based on each labour func-
tion responsibilities, which would make it possible to hire people with disabilities. To the
researchers, it is necessary to evaluate the requested abilities for the performance of dif-
ferent positions in the companies and analyse people with disabilities skills towards their

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possibilities, knowledge, barriers, and facilitators for carrying out such activities. The knowledge application "model" for the companies' requests, clearer at the professional inclusion of a person with disabilities, but common to all other workers, is the aspect of a repetitive activity, of a thought reduced to a private mechanism.

Method

The method and data presented in this article stemmed from one research called *Professional Inclusion of Workers With Down Syndrome in the City of São Paulo*, developed by the Laboratory of Studies on Prejudice (LaEP; Laboratório de Estudos sobre o Preconceito), at Psychology Institute at the University of São Paulo, organised by José Leon Crochick, held during 2017 and published on 2019 (Crochick, 2019). The research was a reapplication of the study called *Professional Inclusion and Life Quality*, coordinated by Carlos Veloso da Veiga. Semi-structured interviews were conducted with 20 workers with Down syndrome, their families, friends, colleagues, and managers. After an interview (pre-test) took place with one of the workers, the instrument — basis for the interviews to come — has reached the following dimensions: general characteristics of the workers; social relationships/interactions; psychological well-being and personal satisfaction; job; self-determination and autonomy; personal skills; community fitness; independent living experiences and community insertion. The observations covered the following dimensions: knowledge application at work; tasks and other achievements; communication; mobility and social interaction. The present article deals with the following dimensions: job realisation, productivity, social relationships in the workplace.

At least two interviewers handled the interviews and observations during the work schedule of these young professionals. All of them have signed an informed consent form. Participants were named with a "P" letter and a corresponding number. The indication of these participants was provided by two institutions in the city of São Paulo which work with people with disabilities inclusion.

Description and Data Analysis

Among 20 participants of this research, 12 worked with services (shops, restaurants, drugstores, etc.), five in companies or offices and three in the educational area. Relatively to each occupation, 12 worked as assistants, four as stockists, which indicates, as in the study of Veiga and Fernandes (2014), that the activities they performed were, in general, of support or simple execution. The average income (R$1,176.84) of the research participants was slightly higher than the national minimum wage (R$954.00) and also than the "Paulista" wage floor (R$1,108.38) at the moment this study took place (2017). Nevertheless, the wages were not high at all.

We should consider that the Brazilian income distribution is unequal. Having this in mind, the salary of these research participants cannot be considered insignificant. A

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possible hypothesis for this income may rely on the type of company or service chosen by these institutions and families. Companies and services with more than 200 employees must have a quota of workers with disabilities, pay salaries, and benefits equal to other workers, and hire them via Brazilian Labor Law (BLL). Also, it should be considered that these amounts were compatible with the wage floor agreements negotiated between companies and unions that covered, above all, medium and large size companies. During this research, 42% of the Brazilian workers were in informality (Instituto Brasileiro de Geografia e Estatística, 2018) — without contribution to social security — receiving low wages, no benefits, and no labour rights. This data is relevant as long as the increase in the number of workers in the informality tends to press down workers' wages in formality.

The participants of this research were on average 28.8 years old and worked for 6 hours daily. They had relative stability on their jobs — an average of 3.6 years in length. Two participants worked for 9 years on the same job and another for 13 years. Three participants did not receive complimentary benefits, and only two did not have a contract via BLL. The complimentary benefits mean a plus to the wage, and the contract via BLL granted labour rights, which meant an advantage compared to the high percentage of informal workers in Brazil, as already demonstrated.

Considering the reasons for hiring these workers, 10 family members responded that it was due to the quotas. Among these, two have indicated that specialised institutions enabled the job; three of the relatives mentioned that the hiring has occurred because of the institutions' roles, and the other five mentioned that the family found the opportunities. According to the employers, 10 participants were hired due to the quota law; another three were hired because they were family friends, and another one was hired through an association working in recruiting and selecting professionals with disabilities.

The quota law (Lei nº 8.213/1991, Article 3) can be understood as an essential policy for these young people to be included in the workplace. It is also remarkable that families had been responsible for five jobs within this sample, which indicates that only the quota law is not enough to support these workers. Presumably, it would be very good to raise awareness the employers about these Down syndrome workers' skills, aiming at the prejudice reduction towards them. The data of this research effectively indicates the variety of activities these workers with mental disabilities can develop, besides so many others, as long as they are prepared for these tasks and are let to perform them, as it happens to the other workers.

Most of the interviewed families (16) evaluated that their relatives earned what they deserved. Among these, three stated to receive more than they deserved; two did not know what to answer, and just one of the families answered that he did not earn what he deserved. The same families informed that the workers liked their job; two said they did

not always like the activities developed, and one said they did not like the job. These data might indicate that their children being hired is enough for them; how much they make, what they do, and if they could have another activity or earn more do not seem relevant. If this is true, the fight against prejudice cannot leave behind the families. Some parents did not believe their children could have a better job and earn more; some said these workers did not rely on this salary, and others answered they never thought about it.

Here are some of their declarations: "he gets more than expected" (P3's family members). "I am not sure if he can get a better job and a higher wage" (P16's mother).

> I do not question if he deserves what he receives. He would not get a job with a better qualification. Friends with Down syndrome work serving coffee, etc. (...) We do not have this worry. He does not work for the money. We save everything on a savings account. (P2's father)

> I think he gets more than he deserves. Considering his case, the company had to give him all the necessary support so that he could adapt and learn his tasks while working. So, (...) in the beginning it was very difficult because he was paid to learn the basics. The company had to invest in his improvement. Therefore, I think that, considering this, his salary was fair enough. (P4's family members)

From this set, only P16's mother questions if her son could receive more. The mother of another young adult, P18, has claimed that her son "could have a better job and a better salary, as he is capable of that". These positions show the possibility of questioning some stereotypes about these young people's skills to have better job positions in the workplace. These positions would contrast to other workers' parents' speeches which confirmed that their children could not get more, expressing a more resigned attitude towards their children's situation.

The following section will analyse the aspects concerning these young adults' satisfaction with the activities they develop in the workplace.

Job Satisfaction

Assunção et al. (2015) searched for identifying the dimensions which determined the worker's satisfaction: fair and adequate compensation; occupational safety and health; an opportunity to use and develop capabilities; opportunity for continued growth and security; social integration; constitutionality and social relevance of work and its importance to life.

All participants answered affirmatively about the sense of achievement at work, and 18 demonstrated satisfaction towards their earnings. Less than half of them was promoted or received a salary increase. Although Veiga and Fernandes (2014) say that there

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is no great incentive for career progression nor salary increase for workers with mental disabilities, seven participants were promoted and/or received a salary increase. During his interview, P1 showed that his work was an essential part of the activities of his life:

> I am happy at work (...) I am working because I like it, it is important to have money, but money is not all in life, the most important is to be happy. I do not know about the possibility of receiving more money in the near future, but I do not care. I want to work, live my life and be happy (...). Another promotion, and another job may come (...) whatever comes is profit to me.

It can be noticed from these reports that part of the workers did not feel the need to change work. However, it should be considered that, as per Coelho et al. (2014) that the fact that some workers feel realised with their jobs could be related to the fact that there are not many job opportunities for people with disabilities. The boredom which "exists in life under bullying at work and under tough job division" (Adorno, 1969/1995, p. 76) seems to be felt by all the workers, but it does not seem to be more important than suffering from the possibility of being excluded from the professional life.

Participant P12 has declared: "I love to work; I do not want to stay at home doing nothing". We can understand that the boredom of "being at home doing nothing" seems to be the reason why the participants prefer working. She showed pleasure by feeling useful and active. At the same time, it is possible to conclude a kind of fear for running out of work, once this would imply being excluded and refrained from social life, a threat which hangs overall at a hierarchical society on which having a job is a structural condition for life maintenance. Thus, P12's speech shows that professional inclusion has a significant meaning for her life quality, which implies not necessarily that her work was tedious, but it would be more pleasant to work than not to work.

The importance of having a job was also pointed out by P19:

> I think it is important to have a job because I can stop and think that many people would like to be at work and cannot. I keep on thinking about the life of those who do not work because sometimes we do not want to go, do not want to wake up early and go to work, but this is part of the world we live in.

Another participant showed gratification for his/her job, saying that: "because I can do what I love to do, to be a professional and to have a career" (P18). P18 believed that "to have a job is important because it gives more opportunities for those who have Down". There is some sympathy in his speech, and he encourages employers to acknowledge the meaning of Down syndrome professionals inclusion in the workplace. Feeling happy at his workplace, P14, in his turn, has even considered it therapeutical. Thus, he had a different perception from what is usually identified as stressful work, which causes pain

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or sacrifice. His activities were effectively varied, not recurring, besides being admired by his colleagues and, especially, by his manager. Nonetheless, this participant said that he could change his job. His expectations searched for better living conditions within possible changes, something obvious among young workers: the expectation of progressing at work and having an increasingly comfortable life.

While showing to be happy with his job, P16 was one of the seven participants who was promoted and received more than when he was hired, and he expected to earn even more. This participant seemed interested in building his own career within the same company. Like P14, he had a plan to have a better life. They were happy to have a job, as indicated by previously mentioned workers, and it is especially important when the economic recession remains in the country.

Other workers (P3, P13, P15, P17 and P20) expressed annoyance for the need to face some limits at work during their performance. P15 declared: "to work makes me happy because I feel I am useful", has also mentioned that he "loved to sell", but this activity was not allowed to him once this was not his job at the company. P17 declared that a dream became true when he started working, but unfortunately, his job would never allow him to have direct contact with customers: "I have the feeling that at work, people keep me training and performing elementary activities. I want to work, to do more interesting things, not only be in training".

These stories express discrimination of these workers due to the hypothetical limitations imposed by their managers and co-workers, generating deprivations and possible situations considered social humiliation.

Another worker (P3), although happy with his job, informed that he would like to change job and work on his own with visual arts. The same happened to P13, who, even feeling happy with his work, did not give up on the idea of changing jobs, as he mentioned that he thought about himself working at a snack bar rather than organising items within a store. About P20, her mother said: "she would prefer to work as a dancer, but it is very hard to sustain herself professionally dancing". With these last stories, the participants presented a comprehension of what would bring them happiness; however, discrimination often denied these possibilities.

In order to continue checking how these professionals are included, we will analyse some aspects related to work productivity: How much their employers and co-workers considered them productive or useful in performing functions assigned to them.

Productivity

Productivity at work can be seen as one of the most critical aspects of professional achievement. The idea of being productive and that the society may enjoy the production is part of these professionals inclusion. However, the requirement and this production exploitation may turn this job into an unpleasant one once this does not consider, necessarily, the workers' interests.

Regarding the workers' comprehension of their activities, 12 have shown an easy comprehension of their managers' and co-workers' instructions, four could understand with some support, and one would comprehend with much help. These data show that it is a false understanding that the Down syndrome workers have difficulties understanding the instructions for work, as long as the communication is done adequately, and this is valid for all workers, with or without mental disabilities.

About the ability to communicate and do elementary calculations, observed in the workplace, 14 participants could express themselves verbally, via gestures or written without help; the other three would do with occasional help, denoting that all the participants could communicate what they intended to do. Nine of them could not do simple calculations, two could do it with help, and two could ask for occasional help. The manager of P2 considered it more important that he would have the basic knowledge for calculations. As math is essential for some activities, it would be important to provide training that could give special attention to teaching this subject to all the workers.

Among other difficulties to be faced by these workers, their co-workers indicated the lack of computer domain, little focus and, sometimes, little empowerment. Regarding the capacities indicated by the co-workers, organisation, communication and attention were mentioned. These indicate that their productivity, and the mentioned limitations, are not so different for all the other workers.

Four of them were praised for their productivity, mainly due to their responsibility, punctuality and perfectionism. P11 was criticised for her flexibility and also for having to deal with stressful situations. P2 was described as orderly and disciplined, doing useful things. Thus, some criticism related to productivity indicated their managers' worries with the production speed: "she is thorough in her work and delivers a well-done job. Her difficulty is towards flexibility. When we have many customers to assist, she feels herself under pressure, as it requires a more rapid rhythm to perform the activities" (P11's co-worker).

> He develops some useful tasks, and some others need to be redone by his colleagues, as file typing. To know how to use Word, deal with the copy machine, the paper shredder, the scissors, these he can do perfectly. Very punctual, orderly and disciplined. Considering productivity, he did not help much but has helped to change the organisational environment. (P2's colleague)

"He is very useful to the company when concerned about product finalisation, but the productivity is worse when compared to his colleagues, his rhythm is different, and I need to follow him up on his activities" (P6's manager).

P8's boss has praised his employee: "he is attentive, fulfils his role and is tidy". However, he has also expressed some criticism, as he "does not take action to deal with routine tasks". P13 was also criticised for his productivity. His co-worker mentioned that

he is productive "if we stick to his foot", that "he is not responsible" and would fulfil his tasks only if "pressed". Besides the previously mentioned difficulties and limitations, it was also mentioned that P13 "does not have a specific job", which may explain his lack of action, as he would need to wait for tasks distribution. This lack of tasks clearly distributed would not mean a kind of discrimination of these workers? One of the employers confirmed that his work was very useful, mainly with the printed documents: "he is very proactive with this".

P16's manager mentioned that, to have production, he would need to follow her up or provide good management of her activities. When asked about P16's responsibility at work, her boss answered that "her productivity varies, but the management makes the necessary adjustments so that she can do a good job". Her boss also said: "her work is useful, as she provides an operational activity that is tedious for others workers but is productive as it helps with her development". We understood her boss declaration as a clear expression of discrimination.

Regarding these workers' inclusion, P14's reports bring new information about the question. His boss would consider him very responsible for the company and his position. During the interview, his position was treated as a generalist, as he would accrue several activities: administrative assistance, work at the reception desk and action as the company office boy. As to his focus, his boss pointed out that when he did not have pending tasks, he would access the internet to get amused, something that would disturb his boss and his colleague, as they consider that idle, although they did not prevent him from doing that. Internet usage seems to be a recurring behaviour in modern social relationships and not something particular to Down syndrome workers. Besides, it clarifies that he did that when he had no activities to perform during the report. To determine that this behaviour would be exclusive within this workers' group seems to be, once more, an expression of discrimination faced by these young people daily.

On the other hand, P5's manager did not fear to compare him with other co-workers. He said that he was the one who best replied to his instructions:

> his work is very useful to the company and his productivity compared to his colleagues is even better, as he delivers 100%, assumes mores than others for they want to do on their own way. He does what he needs to do following the instructions received. (P5's manager)

This "compliment" for the activity being well delivered by P5 as he acknowledges what is told to do seems to indicate that the worker had a good comprehension, was attentive and would consider the requirements and opinions of his boss. However, the report seems to indicate certain passiveness, submission in the order of acceptance. The evaluation on the Down syndrome young worker "being even better" denotes a compensation which the boss aligns with the worker's mental disability, although not

overcoming, remaining thus as a discrimination attitude through a super valued compliment. According to Amaral (1998), if acknowledging others' significant difference (or rejection to it) causes some discomfort, stress, and anxiety, protection measures may be provided to mitigate the discomfort.

P18 was very much acclaimed by his managers. One of them said:

> his work is very useful. He is considered a secret weapon, as he goes out, brings customers in, chats with them and entertains them, making these clients to want to come back. Therefore, he was moved from the branch at neighbourhood I., where he worked and moved to a new [branch] in the neighbourhood. The idea was to bring more customers as he did [at the branch] in neighbourhood I. He has been there at the new branch for 1 month already and has matched the expectations. (P18's manager)

His work was considered very important to the company, as it was requested he should help attract more clients to the new branch. Although the search for greater profits is part of the capitalist ideal, there is no way not to notice that, in this particular case, that mental disability get "spectacularisation" contours. If it is important to point out positive aspects for the inclusion of a Down syndrome worker, it must be considered that, in this case, it has turned into an "attraction", as his difference was used to, maybe, increase business earnings.

P7, P10 and P12 reports indicate the importance of activities performed by them and their communication skills: "she speaks very well in public, learns easily and is well organised. (...) She is human, hugs everyone and is sweet. (...) She fits because she does right everything she is asked to do" (P7's manager).

> She shows communication skills, good relationship with customers, is active, has learning skills, knows how to use a computer. When she does not know, she asks and she memorises the codes very easily. (...) The work she performs, besides pleasing everyone, is a very useful work, essential to all tasks development. She helps her colleagues and also helps to organise the carts with material which the customers will use. (P10's co-worker)

> She can focus on her work and is very nice. She has personal initiative and works with everyone. She is sharp, constant, hygienic, nice. Apart from her difficulties, she is more professional than others who work here. When we have meetings, she is invited and gives important reports, [claiming for] more rest time and packers. (P12's colleague)

These workers' contributions seem to be well evaluated by their co-workers, their managers, and the participants themselves.

As to the Down syndrome workers' productivity, it could be noticed that a meaningful part of the barriers is related to the behaviour of some managers, colleagues and customers. Even though none of them has declared clearly to be against the professional activity of these workers, it can be noticed in their conducts and actions, such as no instruction towards activities to be performed, tasks isolated from customers' space and unnecessary protection. In any case, it is worth reflecting on how well companies are prepared to welcome these workers. The collected data points in another direction: workers were expected to adapt to the rationality of work, but no apparent efforts were observed on employers and colleagues to adapt their own work environment to include them better. It is worth emphasising, to bring this discussion closer to those referring to inclusive education, that integration is different from inclusion, as the latter recognises the need for institutions to change themselves to create similar conditions to improve the general cultural mood (Booth & Ainscow, 2011).

Social Relationships in the Workplace

We will present data collected from the interviews and observations about the Down syndrome workers' social relationships with their managers, co-workers and customers.

According to most of these workers' colleagues, they were not treated differently. There were actions to protect some privileges, such as giving some time off or making schedules more flexible when it happened. These actions could generate harassment as well as hard feelings from other colleagues. When favouring a Down syndrome worker at the expense of other workers, these actions can be considered "positive" discrimination (Amaral, 1998).

When referring to friendship at the workplace, 14 participants thought to have friends as the other four mentioned that, besides being treated very affectionately, they were considered colleagues, not friends, as they did not meet after working hours. The participants tended to be treated the same way as other colleagues in the workplace, with reports of fellowship and sympathy. Some reports mentioned that they were invited and attended the get-together parties. However, the fellowship relationships were generally restricted to the workplace, as they were not invited to tours or parties outside the workplace.

As to the relationships between customers and these workers, it could be noticed, in general, that they could establish friendly relationships. Some companies were well evaluated by the clients just because they hired these workers.

As to colleagues' opinion about customers and suppliers mentioned about these Down syndrome workers, there are some reports to highlight: "people think this is super normal, as part of the company, just like all other employees" (P1's manager); "clients think interesting" (P9's co-worker); "the customer's relationship is good. Some clients congratulate them for his work and the company's action" (P14's manager).

However, some reports showed that some clients felt discomfort with their presence at the workplace and did not like to be served by them, expressing clear discrimination.

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The companies' dependence on the whims of their customers seems to justify the peripheral inclusion of workers with Down syndrome. It is worth mentioning that 12 of them did not interact directly with clients, being very incidental, as expressed below: "he stays more at the storage, does not talk much, but he is polite and welcomes the clients" (P6's co-worker); "she does have much interaction with externals, but I know some are not receptive" (P16's manager).

From these two speeches, the interviewees mentioned the little interaction with the clients when they pointed out that those two workers worked at the shop storage. It should be noted that these workplaces were usually chosen by their employers and not chosen by themselves. In general, it is the employers' responsibility to define the workplace, as this is not the employee's choice. However, the collected data denote repeated situations where these workers with Down syndrome are set apart from customers' view, which brings out questions if these would not be segregation expressions of these young professionals in the workplace.

Considering the responsiveness of these employees' interaction with clients, some employers said the following: "we have received personal feedback and also reports and comments on social networks with very positive reviews from the place. Customers love her. Customers praise her, say she is attentive, polite, kind and very helpful" (P11's manager and associate).

> There was never a direct expression about this subject, but the employee's reaction was very good. There was never glances or postures with non-acceptance or dissatisfaction. He is more at ease, articulate, with more action to things in general. He made new friends, enriched his vocabulary in contact with colleagues and customers. (P18's employer)

> She is very important to the store, for being productive and makes the difference in the store, is attentive and kind to all customers, distinguishes herself from others on the same position. If I need to pay overtime, I prefer to do it for P12. Some clients do not like her while others love her job and her way of working. Those who like her call her by name. (P12's manager)

This good customers' responsiveness shows an important aspect for these workers' inclusion in the work environment and society. That is why it is important not to prevent these workers from establishing relationships with their colleagues and other people at the workplace. When analysing the hiring of people with mental disabilities, some papers (Ávila-Vitor & Carvalho-Freitas, 2012; Carvalho-Freitas, 2012) sustain the corporate brand and the company's environment as essential elements related to the benefits of hiring, as both employees and customers appreciate this conduct. Participant P12 describes his meaning to this corporate brand: "the work is very important at the company because everybody helps. The boss has spoken good things about my job. When I stay home, all customers look for me".

The worker has understood as a positive experience his inclusion in work, felt happy for being part of a whole, realised his importance to the company because "all customers" searched for him.

Closing Remarks

> Living with mentally disabled people, as well as all other disabilities, cultures, genders, ages, skin colour, in appropriate conditions, that is, with mutual cooperation, constant, pleasant, and confronting concepts – the worth of humankind no matter what we are at each historical time –, even not avoiding the absence of criticism and our need to become rational, peaceful and affectionate, these are necessary conditions for an inclusive society. (Crochick, 2019, p. 130)

The professional inclusion of workers with Down syndrome denotes the discrepancy of work conditions (often precarious) for all workers. We found out the fear of social exclusion, unemployment, and meaningless life among this research data. It was also observed a lack of recognition of skills and capabilities of these workers. The impossibility of self-determination in the face of the imposition for being productive was observed at different times during this research, although this definition affects any other worker.

This research also disclosed essential issues over the possibilities of including workers with Down syndrome and guiding better conditions for these professionals. It can point ways of facing different prejudiced expressions towards them, such as discrimination, marginalisation, and segregation.

Among retrograde issues still prevailing, we highlight discrimination on daily processes, where these workers were considered slow or unable to perform their activities. We had also identified segregation moments where these workers were set apart from clients' contact or not invited to participate in parties or meetings with their colleagues outside the workplace. They were also marginalised, above all, when they performed unnecessary tasks, set aside the activities required to the group of all other workers. On the other hand, there were some moments in which they were judged very positively by their colleagues, managers and customers, situations that point out to inclusive processes, fellowship and capability recognition of these workers to carry out activities designed to them. In the last case, the contact hypothesis has some positive aspects (Allport, 1958). However, it is worth saying that setting the prejudice target only on the different social institutions, not considering their work should be to facilitate inclusion, is not, by itself, enough to improve the general cultural environment. This perspective aims to create social conditions favourable to the community between the prejudice targets — in this case, the workers with Down syndrome — and all other people within all social classes, mainly within the institutions, like the school and the labour market. This contact

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facilitates the formation of identifying processes that will deconstruct the arising negative idealisations, in general, from the lack of experience with the targets as common victims of prejudice expressions in this culture. Workers with Down syndrome, just like other people, have dreams, seek to be happy and have the right to live with their fellows in all social areas.

We understand that it is necessary to initiate all efforts so that workers with Down syndrome, and all other workers with some disability, be included in all areas of human coexistence. The fight for the emancipation of all workers in so many processes of exploitation and reification which distinguishes modern social life cannot avoid considering, even contradictorily, the fight for inclusion of all workers, since, in this managed world, to get hired is the primary condition for group and personal life maintenance. As mentioned, the possibility of a freedom glimpse, in the middle of the social domination, allows us to reconcile with the human touch, pointing to the realisation of a full life that should be already possible to everyone.

References

Adorno, T. W. (1995). *Palavras e sinais* (M. H. Ruschel, Trans.). Vozes. (Original work published 1969)

Adorno, T. W. (2019). *Estudos sobre a personalidade autoritária* (V. H. F. da Costa, F. L. T. Corrêa, & C. H. Pissardo, Trans.). Editora Unesp. (Original work published 1950)

Allport, G. (1958). *The nature of prejudice*. Doubleday Anchor.

Amaral, L. A. (1998). Sobre crocodilos e avestruzes: Falando de diferenças físicas, preconceitos e sua superação. In J. G. Aquino (Ed.), *Diferenças e preconceitos na escola: Alternativas teóricas e práticas* (11–30). Summus.

Assunção, R. V., Carvalho-Freitas, M. N., & Oliveira, M. S. (2015). Satisfação no trabalho e oportunidades de desenvolvimento da carreira entre profissionais com deficiência. *Revista Psicologia: Organizações e Trabalho*, *15*(4), 340–351. https://doi.org/10.17652/rpot/2015.4.556

Ávila-Vitor, M. R. C., & Carvalho-Freitas, M. N. de. (2012). Valores organizacionais e concepções de deficiência: A percepção de pessoas incluídas. *Psicologia: Ciênc e Profissão*, *32*(4), 792–807. https://doi.org/10.1590/S1414-98932012000400003

Booth, T., & Ainscow, M. (2011). *The index for inclusion: Developing learning and participation in schools.* CSIE.

Carvalho-Freitas, M. N. de. (2012). Validação do inventário de concepções de deficiência em situações de trabalho (ICD-ST). *Psico-USF*, *17*(1), 33–42. https://doi.org/10.1590/S1413-82712012000100005

Coelho, C. M., Sampaio, R. F., & Mancini, M. C. (2014). Trabalhadores com deficiência: Vivências de prazer e sofrimento. *Psicologia & Sociedade*, *26*(1), 214–223. https://doi.org/10.1590/S0102-71822014000100023

Costa, M. C. A., Comello, D. M., Tette, R. P. G., Rezende, M. G., & Nepomuceno, M. F. (2011). Inclusão social pelo trabalho: A qualificação profissional para pessoas com deficiência intelectual. *Gerais: Revista Interinstitucional de Psicologia*, *4*(2), 200–214.

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Professional Inclusion of Down Syndrome... · Ricardo Casco, Patrícia Ferreira de Andrade, Cintia Copit Freller, Gabriel Katsumi Saito & Roberta Cruz Lima

Crochick, J. L. (Ed.). (2019). *Inclusão profissional de trabalhadores com deficiência intelectual na cidade de São Paulo*. Benjamin Editorial; FAPESP.

Crochick, J. L., Koratsu, L. N., Dias, M. A. L., Freller, C. C., & Casco, R. (2013). *Inclusão e discriminação na educação escolar*. Alínea.

Horkheimer, M., & Adorno, T. W. (1985). *Dialética do esclarecimento: Fragmentos filosóficos* (G. A. de Almeida, Trans.). Zahar. (Original work published 1947)

Instituto Brasileiro de Geografia e Estatística. (2018). *Pesquisa nacional por amostra de domicílios contínua, 2012-2018.* https://biblioteca.ibge.gov.br/visualizacao/livros/liv101678.pdf

Jodelet, D. (1999). Os processos psicossociais da exclusão. In B. Sawaia (Ed.), *As artimanhas da exclusão: Análise psicossocial e ética da desigualdade social* (pp. 53–66). Editora Vozes.

Lei nº 8.213, de 24 de julho de 1991 (1991). http://www.planalto.gov.br/ccivil_03/leis/l8213cons.htm

Lorenzo, S. M., & Silva, N. R. (2017). Contratação de pessoas com deficiência nas empresas na perspectiva dos profissionais de recursos humanos. *Revista Brasileira de Educação Especial*, *23*(3), 345–360. https://doi.org/10.1590/S1413-65382317000300003

Marcuse, H. (1968). *Eros e civilização: Uma interpretação filosófica do pensamento de Freud* (A. Cabral, Trans.). Zahar. (Original work published 1955)

Marcuse, H. (1979). *A ideologia da sociedade industrial: O homem unidimensional.* (5th ed., G. Reboá, Trans.). Zahar. (Original work published 1964)

Simonelli, A. P., & Camarotto, J. A. (2011). Análise de atividades para a inclusão de pessoas com deficiência no trabalho: uma proposta de modelo. *Gestão & Produção*, *18*(1), 13–26. https://doi.org/10.1590/S0104-530X2011000100002

Veiga, C. V. da, & Fernandes, L. M. (2014). *Inclusão profissional e qualidade de vida*. Edições Húmus.

Zarur, A. P. L., & Domingues, A. L. (2017). *A inserção da pessoa com síndrome de Down no mercado de trabalho* [Undergraduate thesis, Unisalesiano].

Biographic Notes

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Effectiveness and Efficiency in Associations of Parents and Friends of the Disabled Persons From Minas Gerais

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Abstract

As social management is a current discussion in organizational studies, this article seeks to understand and explain the effectiveness and efficiency of the Associações de Pais e Amigos dos Excepcionais (APAE, Associations of Parents and Friends of the Disabled Persons) in the state of Minas Gerais, Brazil, based on their statutory mission that works as a guideline for their practices. The analysis is based on the point of view of APAEs' managers under the three dimensions of their mission: services rendering, improvement of the quality of services and defense of the rights of persons with intellectual disability, understanding the dimensions as systems interacting with the external environment, based on a survey applied to a representative sample of 199 randomly selected APAEs, segmented into three pre-defined clusters according to size. This questionnaire was self-administered by the managers and directors of the APAEs from the sample. It comprises a series of questions based on 54 indicators presented in the three dimensions observed in the statutory mission of the APAEs. In order to analyze the effectiveness and efficiency based on those indicators, effectiveness and efficiency indices were built. These indices were submitted to several statistical analysis techniques, taking the systemic theory and the concepts of effectiveness and efficiency as references. The results obtained indicate the existence of structural homogeneity on the APAEs, regardless of their eight clusters distributed by quartiles according to their different levels of effectiveness and efficiency (low, average, high, and very high). It was not possible to achieve an explanatory quantitative model of the effectiveness and efficiency levels of the APAEs considering the influence of the internal and external variables to which they were related.

Eficácia e Eficiência nas Associações de Pais e Amigos dos Excepcionais de Minas Gerais

Resumo

Como a gestão social é uma discussão atual nos estudos organizacionais, este artigo busca contribuir para compreender e explicar a eficácia e a eficiência nas Associações de Pais e Amigos dos Excepcionais (APAE) de Minas Gerais, Brasil, tomadas do ponto de vista da sua missão estatutária como orientadora de suas práticas. A análise é feita com base na visão dos gestores das APAE sob as três dimensões da sua missão: oferta de serviços, melhoria da qualidade dos serviços e defesa de direitos das pessoas com deficiência intelectual, entendendo-as como sistemas em interação com o meio ambiente externo. Com base num inquérito por questionário aplicado a uma amostra representativa de 199 APAE selecionadas aleatoriamente, foram segmentadas por três clusters pré-definidos segundo a dimensão (porte). Esse questionário foi auto

administrado pelos gestores e diretores das APAE, da amostra, sendo composto por uma série de perguntas em função de 54 indicadores presentes nas três dimensões observadas na missão estatutária das APAE. Por forma a analisar a eficácia e a eficiência com base naqueles indicadores, construíram-se índices de eficácia e eficiência. Tendo como referencial a teoria sistêmica e os conceitos de eficácia e eficiência, submeteram-se esses índices a várias técnicas de análise estatística. Os resultados obtidos apontam para existência de homogeneidade estrutural das APAE, independentemente dos seus oito clusters formados com base na distribuição por quartis dos seus diferentes níveis de eficácia e eficiência (baixo, médio, alto e elevado), não tendo sido possível chegar a um modelo quantitativo explicativo dos níveis de eficácia e eficiência das APAE, considerando a influência das variáveis internas e externas com que foram relacionados.

Introduction

This article is part of the debate about the management of civil society organizations (CSOs) and aims to understand how effectiveness and efficiency can be verified in these types of organizations.

According to Steinberg and Powell (2006), there are multiple definitions and categorizations for these types of organizations, which generates much confusion, such as non-governmental, third sector, non-profit, non-economic, philanthropic, voluntary organizations, of the independent sector, among others.

These multiple definitions have generated much confusion over time, leading the Brazilian Congress to approve Law no. 13.019 (Lei n° 13.019), of July 31, 2014, which defines non-profit organizations and those originating from civil society as CSOs.

The study aimed to understand the effectiveness and efficiency of the Associações de Pais e Amigos dos Excepcionais (APAE; Associations of Parents and Friends of Disabled People) in the state of Minas Gerais, Brazil. CSOs have been created to meet the needs of civil society both to support people with intellectual and multiple disabilities in the process of qualification and rehabilitation and partnership with public policies developed by the Brazilian State.

Therefore, this investigation was based on a systemic approach and organizational effectiveness and efficiency concepts. Through a quantitative approach, a self-applied questionnaire was sent to a random sample of 199 managers from APAEs. Here, the effort was to seek elements that help us quantitatively understand the effectiveness and efficiency in the APAEs network in Minas Gerais from the perception of the organizations' managers, understanding it as part of a system and considering its heterogeneity when offering services.

Descriptive, cluster, quartile analyses Pearson's correlation coefficients were carried out, and a multiple linear regression model was built to try to find an explanatory model of the effectiveness and efficiency in the Minas Gerais APAEs. Only the quartile

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analysis allowed the segmentation of the APAEs into eight clusters, and it was not possible to reach the desired explanatory model of the effectiveness and efficiency of the APAEs.

Theoretical-Conceptual Framework

The general growth of complexity and uncertainty present in the contemporary world slowly (but inevitably) leads us to an overview of the world that, according to Rosnay (1975), requires an effort to synthesize what the systemic approach entails as a method of understanding the phenomena of contemporary society. Thus, according to Durand (1979/1992), we have three major categories of systems: the physical, atomic, and solar systems. Living systems are ecology and biology; social systems include work organizations and the family; there are also economic and political systems.

A system is "a set of elements that relate to each other, forming a whole, and its structure is formed by its elements (subsystems), being the living element - the person or the group - the transforming element within the organizations", according to Bériot (1992/1997, p. 21). Furthermore, according to this author, a system will have more opportunities to optimize its results if there is consistency between its purpose and its actions. Then, it is necessary to know the relationships between the individuals that compose it, as this interaction allows knowledge of the system and not the individuals themselves. To act on a system, one must commit to its current functioning and not to the history or causes that explain its functioning deficiencies. Likewise, it is essential to consider the natural tendency of the elements of the system that are resistant to change. Furthermore, Bériot (1992/1997) points out that "the adaptability of a system depends on the balance between the set of rules (the norms), which can prevent a disorganized reaction to change" (p. 45). Finally, the information circulating in the system, and the conditions for passing this information along, make it possible to guide or misguide the change to be made.

In turn, Brito (1989) understands a system as "a set of symbols through which we describe the empirical behavior that characterizes the organization" (p. 35). CSOs are non-profit and autonomous, not linked to the government. In general, the product of the activities of these organizations does not generate goods or financial resources, which makes them dependent on donations and governmental partnerships. Furthermore, the statutes define their purpose, and their organization is characterized by informality, with practically no written rules and procedures. Moreover, although there is a planning process, it is not formalized. There is also no systematization of data for evaluation purposes (Tenório, 2009).

Drucker (1990/1994) adds that "these organizations exist to bring about changes in individuals and society" (p. 3). Therefore, the APAEs exist to transform the relationship of Brazilians with disabilities with society. Thus, this type of organization should not be a mere service provider but consider its end-user as an agent of transformation of individuals and society (Brito, 1989). However, from a sociological perspective, CSOs

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have some points in common with other work organizations, as they involve social formations with specific members and clear, internal differentiation of roles. Furthermore, they present a rational orientation towards their objective, which is how to study them as a social system (Brito, 1989). According to Drucker (1990/1994), this orientation must be clear and objective and be expressed in the organization's mission. That is of utmost importance for setting concrete action goals and for the commitment of individuals to the objective to be achieved.

Therefore, for a CSO like APAE to provide good quality service, it is not enough for parents, people with intellectual disabilities, and friends to get together and seek resources to support the association. It is equally necessary to ensure that the resources obtained are allocated in the best possible way and that the work is carried out correctly. Thus, to achieve the objective, it is necessary to have a clearly and objectively defined mission and goals and efficient management of the parts that make up this association: administrative and financial areas, educational, health, and social assistance.

These goals must be evaluated based on the mission established and described in Chapter 1, Article 3rd of the standard statute:

> Art. 3rd – The APAE's MISSION is to promote and articulate actions to support rights and preparedness, guidance, provision of services, and support to the family, improving the quality of life of disabled people, and building a fair and solidary society. (APAE Brasil, 2015)

This set of intertwined elements forms the social system, with subsystems in its structure, the living element — the person or the group — the transforming element within organizations. However, these elements can behave differently depending on the system inserted and influenced by elements with which they are reciprocally related. They may even be divided into smaller elements according to the level of observation that we intend. In this case, the smallest human element considered in the systemic approach is the person (Bériot, 1992/1997). Also, according to this author, a system will have more opportunities to optimize its results if there is consistency between its purpose and its actions and if we know the relationships between the individuals it comprises.

The way to verify whether the objectives of an APAE or any other form of work organization are being achieved is through effectiveness and efficiency measures. According to Cameron (1986), despite effectiveness and efficiency being one of the organizational studies' central concepts, there is some confusion. However, this confusion becomes understandable when we realize that it occurs because organizations change and, consequently, the organizational model of effectiveness and efficiency will also change. Any model used to measure these concepts will be dynamic and can be directly affected by organizational changes.

According to Robalo (1995), the terms effectiveness and efficiency are not equivalent, but the distinction between them is not always established in the same way. Effectiveness is an absolute concept, as an APAE can be effective or ineffective in achieving or not achieving its goal. The goal achieved must be the one described in its mission

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and thought of regarding APAE as a whole, in a systemic perspective, considering the conditions required for its maintenance and the dynamics of its relationships with other institutions in the municipality. On the other hand, efficiency refers to the best way to reach a particular objective. It is, strictly speaking, a relative and not an absolute concept. That is, one APAE can be more efficient than another or others; one service or technique may be more efficient than another. Therefore, there will not be just one efficient APAE, service, or technique, but those that are more or less efficient than the other(s).

Castro (2006) adds to this understanding by stating that efficiency is not concerned with goals; it is part of the operational activities; that is, it is focused on internal aspects of the organization. Thus, effectiveness is what concerns goals in achieving the organization's objectives. An organization, then, can be efficient and not effective and vice versa. Ideally, it would be equally effective and efficient.

Briefly, Tenório (2009) defines that "effectiveness is doing what must be done, that is, meeting the specific objective" and "efficiency is the best way to do something with the available resources" (p. 18), and presents the following organizational performance hypotheses (Table 1).

PERFORMANCE	EVALUATION
Effective and efficient	The proposed objectives were achieved, with the least use of available resources
Effective but not efficient	The objectives were achieved, but with greater consumption of resources than expected
Efficient but not effective	The resources were used as planned, but not all the expected objectives were achieved
Not effective and not efficient	The objectives were not achieved, and more resources than expected were used

Table 1 *Summary of hypotheses for analyzing the performance of organizations*

Source. Tenório, 2009, p. 19

Conversely, as Cameron (1986) stated, there is no consensus on the best or a good set of indicators to measure organizational effectiveness and efficiency, with no specifiable limits. However, different models are useful to research on different circumstances and must start with a clear organizational mission to define the best way to carry out the activities in the organizations.

Added to this is that organizational effectiveness and efficiency, according to Cameron (1986), are problem-oriented, not theoretical, constructs. Therefore, it can be said that the act of managing an APAE encompasses the pursuit of effectiveness and efficiency in its everyday activities, from a systemic perspective based on the clear and straightforward definition of its mission, linked to external issues that may impact it.

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Method

We consider this article an exploratory study, as there is little accumulated and systematized knowledge about efficiency and effectiveness in APAEs. It is also a field study; an empirical investigation carried out in APAEs in Minas Gerais, which searches the explanatory elements of the phenomenon (Gil, 2008), based on a quantitative methodological approach.

The definition of the sample followed the teachings of Laville and Dionne (1997/1999), for whom the representative character of a sample depends on how it is established. In this study, the sample was selected randomly from a complete list of APAEs. That is a probabilistic sample, allowing all APAEs operating in the state of Minas Gerais the opportunity to participate. The sample size (199) was determined based on the finite population of 408 APAEs at the confidence level of 95% (n^1; Equation 1).

$$n = \frac{N \cdot \hat{p} \cdot \hat{q} \cdot (Z\alpha/2)^2}{\hat{p} \cdot \hat{q} \cdot (Z\alpha/2)^2 + (N-1) \cdot E^2} \tag{1}$$

$$n = \frac{408 \times 0{,}25 \times (1{,}96)^2}{0{,}25 \times (1{,}96)^2 + (408 - 1) \times 0{,}05^2} = 199 \; (rounded \; up)$$

Subsequently, this random sample was stratified, considering the three clusters constructed according to the size of the APAE. That is defined by the Federation of APAEs of the state of Minas Gerais, based on its provision of service: size 1 APAEs offer only education service (authorized by the State Council of Education), or social assistance (National Register of Social Assistance Establishments), or health (National Register of Health Establishments); size 2 APAEs offer two of these services; and, the larger ones offer the three services (Table 2).

Clusters	Number of Associações de Pais e Amigos dos Excepcionais	Stratified sample
Size 1 (offer one service)	84	41
Size 2 (offer two services)	137	67
Size 3 (offer three services)	187	91
Total	408	199

Table 2 *Size of the population and sample of Associações de Pais e Amigos dos Excepcionais stratified by cluster*

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[1] Sample size (*n*) based on population proportion estimate. Sample size was calculated based on the formula above and, as *p* and *q* are unknown, they were replaced by 0.5, obtaining the presented estimate.

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It should be noted that a 10% APAEs percentage was drawn as a reserve in case replacement was required. This survey was self-administered (Almeida & Botelho, 2006) by the interviewees, consisting of a series of questions based on the three dimensions observed in the statutory mission of the APAEs: service provision, improving the quality of life, and defending rights.

From the perspective of *service provision*, the questions were based on the knowledge of APAEs from Minas Gerais and sought to include aspects of the four functions of administration (planning, organization, direction, and control), the installed capacity of the APAEs, the quality of the services provided, the results achieved with the users, the satisfaction of the users with the services offered and the innovations incorporated into the services.

From the perspective *of improving quality of life,* the model applied in intellectual disability was developed by Schalock and Verdugo (2007), added to the teachings of Veiga et al. (2014). On that basis, questions were defined regarding the inclusion of people with intellectual and multiple disabilities in the formal labor market, their integration into the community, the development of their personal skills, their social relationships and interactions, aspects of their self-determination and independent life, in addition to aspects of their psychological well-being and personal satisfaction.

From the perspective of *defending rights*, the questions were based on the Convention on the Rights of People with Disabilities incorporated into the Brazilian Constitution of 1988 (Decreto n° 6.949, 2009).

After the questions were defined, they were submitted to a panel of experts working in the organizations studied. The panel consisted of a speech therapist, a social worker, a social scientist, an art specialist, an occupational therapist, an administrator, and an educator, who contributed to adapting them to the reality of the Minas Gerais APAEs.

Then, the questionnaire was tested on a small sample of 16 APAEs from Minas Gerais, not drawn in the random sample. The aim was to adapt the questionnaire in terms of understandable language and adequate intellectual level (Almeida & Botelho, 2006) and avoid potential problems given the heterogeneous profile of the Minas' APAEs' managers.

Finally, the managers were asked whether, in their opinion, those issues were present or not in the respective APAEs during 2019.

After performing the pre-test, the questionnaire was completed and sent to the 199 APAEs in Minas Gerais from the random sample, using Google Forms. In addition to being free, this online tool enabled respondents' access from any place and at any time, streamlining data collection and obtaining a total of 199 responses complying with the established dimension.

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Organizational Traits: Managers' Perspective on Associações de Pais e Amigos dos Excepcionais Network in Minas Gerais

This aspect describes the main quantitative traits contributing to understanding the differences and similarities between the three sizes of APAEs regarding the three dimensions that make up their mission. This description is based on evidence established from frequency analysis of the data collected through the questionnaires and data from some official systems of the Brazilian government: Unified Social Assistance System, National Education System, and Unified Health System.

Dimension of the Associação de Pais e Amigos dos Excepcionais and of the Municipality

Comparing the APAEs by size and their municipalities dimension, we observe that 48.8% of size 1 APAEs are located in micro-municipalities (up to 10,000 inhabitants), 39% in small municipalities (from 10,001 to 25,000 inhabitants), and 12.2% in medium-sized municipalities (from 25,001 to 55,000 inhabitants). Therefore, the smaller ones are mostly located in micro and small municipalities.

Regarding the per capita gross domestic product (GDP) of these municipalities, compared to the average per capita GDP of R$33,593.82 and R$29,223.00 in Brazil and Minas Gerais (2018), respectively, it appears that only 14.6% of these municipalities surpass the average Brazilian GDP, and 17.1% surpass the Minas Gerais average. The GDP in 82.9% of the small-sized APAEs municipalities is below the average per capita for Brazil and Minas Gerais.

The medium-sized APAEs, that is, those that offer two services (education and health, or education and assistance, or assistance and education), are located mostly in micro-municipalities up to 10,000 inhabitants (28.4%) and medium-sized municipalities from 25,001 to 55,000 inhabitants (56.7%). The others are divided: 8.9% are located in small municipalities (from 10,001 to 25,000) and 6.0% in large municipalities (over 100,000 inhabitants).

As for the per capita GDP of the municipalities where the medium-sized APAEs are located, we find that only 9.0% of them are above the national average. This percentage increases to 13.4% when compared to the Minas Gerais average. Therefore, 86.6% of the municipalities where the medium-sized APAEs are located have per capita GDPs lower than the Brazilian and Minas Gerais averages.

When we look at the data for the larger APAEs, those that offer three services, we notice a concentration of large APAEs in small (from 10,001 to 25,000) and medium-sized municipalities (from 25,001 to 100,000), 43.8% and 35.2%, respectively, while 11% of them are located in micro-municipalities with less than 10,000 inhabitants and 10% are located in large municipalities (over 100,000 inhabitants). So, the large APAEs are mainly located in small and medium-sized municipalities.

As for the per capita GDP of the municipalities where the largest APAEs are located, only 16.4% of the municipalities have a per capita GDP above the Brazilian average. This percentage grows to 24.2% when we consider the Minas Gerais average. Therefore, more

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than 70% of the municipalities where the largest APAEs in Minas Gerais are located have per capita GDPs below the Brazilian and Minas Gerais averages.

Distribution of the Human Resources of the Associações de Pais e Amigos dos Excepcionais

This information was requested from all APAEs in the sample. Its composition was systematized and broken down according to the sizes of the APAEs. In size 1 APAEs, it appears that 29.3% of them, considering only the human resources dimension, are similar to micro-companies (from one to nine employees), and the remainder, 70.7%, are similar to small businesses (from 10 to 99 employees). Most APAEs, about 87.8% of them, present an asymmetrical distribution of technical and administrative employees, in favor of technical employees, except for two that have additional administrative employees. Four APAEs have a symmetrical distribution between technical and administrative employees.

In size 2 APAEs, we observed that eight APAEs had fewer than 10 employees. Observing only this dimension, this is equivalent to a micro business and represents 11.9% of the total APAEs of this size. The remainder, 88.1%, is classified as small companies.

As for the distribution of employees between technicians and administrative staff, it can be observed that most APAEs, 97.0%, are asymmetrical, having a more significant number of employees in the technical area compared to those in the administrative area. The exception is that three APAEs have a higher percentage of administrative employees than technicians. Only one APAE has a balanced relation between the number of technical and administrative employees.

In the APAEs that offer the three services (education, health, and social assistance), 3.3% are similar to medium-sized companies, and 95.6% are similar to small companies when we look only at the number of employees. Regarding the distribution of employees between technicians and administrative staff, 4.4% have symmetrical distribution between the two types of employees, and 95.6% have asymmetrical distribution between technical and administrative employees. Only 3 of these APAEs have more administrative than technical employees; the others have a higher percentage of technical staff.

Distribution of Users of the Associações de Pais e Amigos dos Excepcionais

Data on users of the APAEs were collected from the official systems of the Unified Social Assistance System (Secretaria Nacional de Assistência Social, n.d.) and the National Education System through their censuses (Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira, 2020), and from the Unified Health System through the deliberations of the goals of the services of the care network for people with disabilities in Brazil (Deliberação CIB-SUS/MG n° 1.404, 2013; Deliberação CIB-SUS/MG n° 1.403, 2013).

In size 2, there are six APAEs, 9.0% of the total, without any user information in the official systems, and 19 APAEs, 28.4% of the total, with information from only one of the services offered. That means that the APAE either did not inform existing users in one of the official systems or has a health service that supports users of other services and is not part of the care network.

Data for the size 3 APAEs show that 62.6% of them are from the care network for people with disabilities with specific public funding. Therefore, the number of users corresponds to their goals deliberated by the public-private partnership. In addition, eight APAEs present data from only two services, 8.8% of the total. That indicates that they did not inform users of one of them, and/or they have a health service that is not part of the care network, which supports users of another service.

When comparing the number of users of size 1 APAEs with the estimated population of people with intellectual disabilities (PWID) in the municipality, apparently, two APAEs have more users than the Instituto Brasileiro de Geografia e Estatística estimate of 1.4% of the population. Regarding the other APAEs of the same size, most have fewer users than 50% of the estimated PWID population. Of these 23 APAEs, nine have fewer users than 15% of the estimated population.

In size 2, seven APAEs have more users than the estimated PWID population. Among the others, 25.4% have more users than 50% of the estimated population, and 53.7%, nine APAEs have fewer users than 50% of the estimated population.

In the larger APAEs, 11 (12.1%) have a higher number of users than the estimated PWID population in the municipality; 17.6% have more users than 50% of the estimated population of the municipality, and 70.3% have fewer users than 50%. Of these, 18.7% have 15% fewer users than the estimated population of the municipality.

DIMENSION OF THE ASSOCIAÇÕES DE PAIS E AMIGOS DOS EXCEPCIONAIS NETWORK IN MINAS GERAIS: PROVISION OF SERVICE, IMPROVING THE QUALITY OF LIFE AND DEFENDING RIGHTS

These data are the frequency analysis results from data collected from the self-administered questionnaire in the APAEs of the random sample. They consider the three dimensions of the institutional mission of the APAEs: provision of service, improving the quality of life of PWID, and defending their rights.

Regarding the provision of services, we found that in the administrative and financial organization of APAEs, fundamental for a good provision of services, there is a weakness in the people management process (recruitment/selection, training/development, and performance evaluation). The data show that all APAEs had lower completion percentages in this process, emphasizing the lack of planning and organization of a structured program for training employees. Only 29.3% of the size 1, 20.9% of the size 2, and 44.0% of the size 3 have it.

Regarding meeting the demands of the PWID in the municipality, it appears that the APAEs are not able to meet all the demands, causing waiting lines. In APAEs that offer only one service, the waiting lines correspond to 26.8% of users. That increases to

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40.3% when offering two services and 59.3% when offering all three services. That demonstrates that the greater the number of services offered, the longer the waiting line to join the APAEs. This waiting list is also significant because only between 60% and 65% of APAEs do not have a user's "exit door" established in the services offered, suggesting that users enter but do not leave, which reduces the service capacity of APAEs.

According to APAEs managers' perception, more than 65% of them (depending on the number of services offered) organize these services based on the needs of the PWID, identified through multidimensional assessment applied in their care plans and monitored and evaluated by validated instruments. However, the number of APAEs that measure their results is less than that of APAEs that assess their results (Table 3) with their users without using any standardized and validated measuring instrument.

Type of Associações de Pais e Amigos dos Excepcionais	Measure results	Analyze results
Size 1	65.9%	73.2%
Size 2	64.2%	83.6%
Size 3	67.0%	76.9%

Table 3 *Percentage of Associações de Pais e Amigos dos Excepcionais that measure and evaluate results*

It can also be verified that the APAEs, generally do not listen much to their users (PWID and their families) regarding satisfaction with the services provided. Still, the managers of the smaller APAEs (size 1) listen more than those of the larger APAEs that offer two and three services; then again, the APAEs offering two services listen more than those offering three services. That leads us to think that, in the managers' perception, the larger the APAE, the less they listen to users.

Regarding improving the quality of life of PWID, the promotion of inclusion in the formal labor market is not very developed in the APAEs, increasing as more services are offered. It can be seen in sizes 2 and 3, a higher percentage of APAEs which support former users (workers) placed in the labor market (44.8% and 63.7%, respectively), developing activities with these former users and employing companies, in making the necessary adjustments for the accommodation of the companies' workgroups to the presence of the difference, such as adequacy of activities of positions, jobs, awareness of the staff for insertion of PWID in the team, among others.

As for providing opportunities for PWID to participate in the community, the APAEs in Minas Gerais reach high percentages. In 100% of APAEs providing 1 type of service, PWIDs are encouraged to participate in local social activities. In those providing two services, the percentage is 97%; and, in those providing three services, it is 98.9%.

In developing personal skills, a lower percentage of APAEs carry out actions to develop independent mobility. In size 1 APAEs, this number is 58.5%; in size 2 APAEs, it is 55.2%; in size 3 APAEs, it is 65.5%. High percentages were observed about the development of care and self-care actions (82.9% APAEs size 1, 83.6% APAEs size 2 and

90.1% APAEs size 3), body language, cognition and communication (78.0% APAEs size 1, 80.6% APAEs size 2, and 93.4% of size 3).

The evidence criteria indicate that the percentages of APAEs that develop actions to stimulate social relations and interaction exceed 85%. That points to a concern, according to APAE managers, with encouraging the construction of social relations, of interaction and support networks. This concern extends to the achievement of autonomy and independent life, although it occurs slightly less than social relations and interaction issues. Activities to address these skills are carried out by more than 80% of APAEs of all sizes. Finally, more than 80% of the APAEs identify the emotional and life aspects that affect the psychological well-being and personal satisfaction of the PWID.

On the one hand, regarding the advances of the general principles of the Convention on the Rights of People with Disabilities, the actions developed aimed at respecting the PWID's dignity stand out as positive. However, the provision of legal services that guarantee their rights is still low, with percentages of 53.7%, 56.7%, and 61.5% in size 1, 2, and 3 APAEs, respectively. On the other hand, as a negative highlight, we have low percentages of participation of the PWID in political and public life, with little encouragement for the creation of representative organizations for the PWID, such as Municipal Councils for Persons with Disabilities, or their participation in the organizations of management and administration of the APAEs.

These traits demonstrate that the size of APAE has little influence on its differentiation, indicating less heterogeneity than was initially thought.

"Portraits" of Associações de Pais e Amigos dos Excepcionais Network in Minas Gerais: Configurations and Dynamics

Initially, we created 13 indicators referring to the three dimensions of the statutory mission of the APAEs, based on the responses of the managers of the 199 APAEs to the questionnaires sent to them. For this purpose, we used the Statistical Package for Social Sciences (SPSS). The APAEs will use these indicators to follow up, monitor, and evaluate the actions that make up the *effectiveness indices* and the *efficiency index* of APAEs network in Minas Gerais.

For the dimension of the *provision of service*:

1. The administrative and financial organization indicator measures APAE's performance in the four basic functions of administration: planning, organization, direction, and control. They are composed of three evidence criteria that measure the institution's efficiency.

2. The installed capacity indicator measures APAE's capacity to meet the demands of people with intellectual disabilities in the municipality. They are composed of three evidence criteria that measure the institution's efficiency.

3. The service quality indicator measures APAE's services organization according to the need to support people with intellectual and multiple disabilities. They are composed of three evidence criteria that measure the institution's efficiency.

4. The results indicator measures the individual results of APAEs' services offered to people with intellectual and multiple disabilities. They are composed of three evidence criteria that measure the institution's efficiency.

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5. The user satisfaction indicator measures the satisfaction of APAE's users (persons with intellectual disabilities and their families) of the services offered. They are composed of three evidence criteria that measure the institution's efficiency.

6. The innovation indicator measures APAE's ability to prospect and use innovative assistive technologies. They are composed of three evidence criteria that measure the institution's efficiency.

For the dimension of *improving the quality of life*:

7. The employment indicator measures APAE's activities that support the inclusion of people with intellectual and multiple disabilities in the formal labor market. They are composed of three evidence criteria that measure the institution's efficiency.

8. The community integration indicator measures APAE's actions that provide people with intellectual and multiple disabilities opportunities to participate in community activities. They are composed of three evidence criteria that measure the institution's efficiency.

9. The personal skills indicator measures APAE's activities supporting personal, productive, and leisure experiences to people with intellectual and multiple disabilities. They are composed of three evidence criteria that measure the institution's efficiency.

10. The social relations and interaction indicator measures APAE's activities that support people with intellectual and multiple disabilities to build interpersonal and social relationships. They are composed of three evidence criteria that measure the institution's efficiency.

11. The self-determination and independent living indicator measures APAE's activities that support the autonomy and independence of people with intellectual and multiple disabilities. They are composed of three evidence criteria that measure the institution's efficiency.

12. The psychological well-being and personal satisfaction indicator measures APAE's activities that promote self-concept and the perception of emotional and life situations of people with intellectual and multiple disabilities. They are composed of three evidence criteria that measure the institution's efficiency.

For the dimension of *defending rights*, the following indicator was created:

13. The defending rights indicator measures APAE's development, promoting people with intellectual and multiple disabilities to participate in political and public life. They are composed of 18 evidence criteria, of which nine measure the efficiency and nine measure the institution's effectiveness.

We performed the cluster analysis using the Euclidean distance to associate the APAEs into four clusters based on these indicators. This experience resulted in a mega cluster formed by almost all the APAEs in the sample (196) and three others composed of a single APAE. This result denoted the existence of great homogeneity for almost all APAEs in Minas Gerais, regardless of their size. This homogeneity remained when using the Euclidean quadratic distance and/or trying to reduce the number of clusters.

Cluster Configurations of Associações de Pais e Amigos dos Excepcionais Network in Minas Gerais

The use of cluster analysis pointed to a homogenization of the group of APAEs, making it impossible to separate them by different levels of effectiveness and efficiency. Thus, it was decided to group the APAEs using a typological classification test based on the quartile analysis of the indices of effectiveness and efficiency, whose values vary between 0 and 27 points, minimum and maximum values of effectiveness or efficiency possible to be attributed to each APAE. The results of the quartile analysis allowed us to

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group the APAEs into eight groups (clusters) under the scores obtained and their positioning in a given quartile, as shown in Table 4.

Quartiles	25%	50%	75%	100%
Effectiveness Indices	0–14	15–18	19–22	23–27
Efficiency indices	0–16	17–21	22–24	25–27
Levels	Low	Average	High	Very high

Table 4 *Quartile distribution of index scores and their levels of effectiveness and efficiency*

Describing the Associações de Pais e Amigos dos Excepcionais

This item presents the various scenarios of the APAEs, based on the eight clusters, four of which presented symmetries between the attributed qualitative levels of effectiveness and efficiency and another four dissymmetries between these levels. Cluster 1 has the largest number of APAEs (36) and has low effectiveness and efficiency measures. It is followed by clusters 2, 3, and 4 presenting respectively, 28 APAEs with very high effectiveness and efficiency, 18 with high effectiveness and efficiency, and 23 with very high effectiveness and efficiency. There were more APAEs in this group with symmetry between effectiveness and efficiency: 64 between low and medium effectiveness and efficiency and 41 between high and elevated effectiveness and efficiency. Clusters 5,6,7, and 8 show asymmetry between effectiveness and efficiency. At the lowest levels are clusters 5 and 6 (17 APAEs with varying effectiveness and low efficiency, and 18 with low effectiveness and varying efficiency). At the highest levels, clusters 7 and 8, there are 35 APAEs with average effectiveness and high efficiency and 24 with high effectiveness and average efficiency. In the group of APAEs that present asymmetric levels of effectiveness and efficiency, there are more APAEs with average and high effectiveness and efficiency (59), and 35 APAEs that showed low effectiveness or low efficiency, as shown in Table 5 below.

Clusters	Effectiveness and efficiency levels	Frequency
1	Low effectiveness and efficiency	36
2	Average effectiveness and efficiency	28
3	High effectiveness and efficiency	18
4	Very high effectiveness and efficiency	23
5	Varied effectiveness and low efficiency	17
6	Low effectiveness and efficiency	18
7	Average effectiveness and very high efficiency	35
8	Very high effectiveness and average efficiency	24
Total	-	199

Table 5 *Distribution of Associações de Pais e Amigos dos Excepcionais by cluster and levels of effectiveness and efficiency*

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Analyzing the territorial distribution of APAEs by clusters across the 12 administrative regions of the state of Minas Gerais, it is possible to verify a large dispersion (Figure 1).

■ Noroeste de Minas	■ Cluster 1
■ Norte de Minas	■ Cluster 2
■ Jequitinhonha	■ Cluster 3
■ Vale do Mucuri	■ Cluster 4
■ Triângulo Mineiro/Alto Paranaíba	■ Cluster 5
■ Central Mineira	■ Cluster 6
■ Metropolitana de Belo Horizonte	■ Cluster 7
■ Vale do Rio Doce	■ Cluster 8
■ Oeste de Minas	
■ Sul/Sudoeste de Minas	
■ Campo das Vertentes	
■ Zona da Mata	
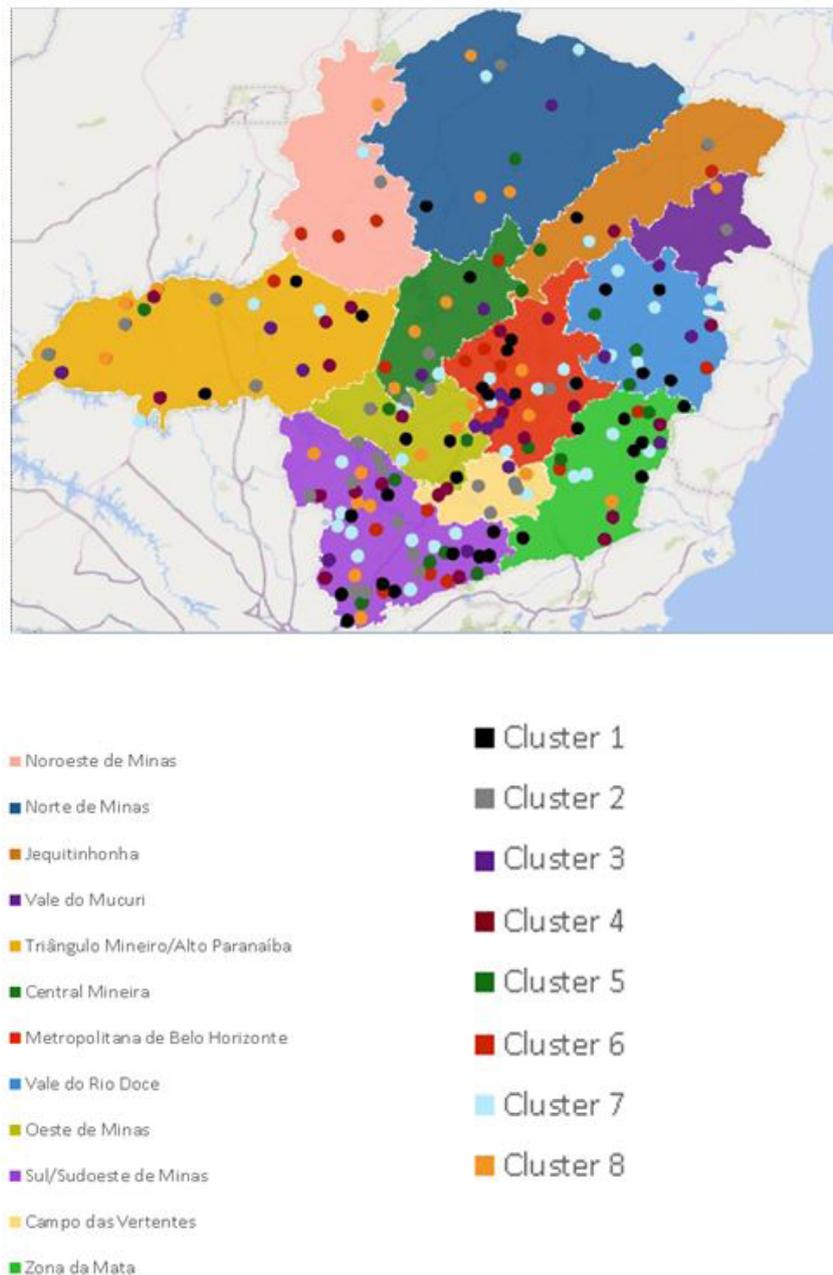
Figure 1 *Territorial distribution of the eight clusters*

APAEs with low effectiveness and efficiency (cluster 1) are concentrated in the metropolitan regions of Belo Horizonte and Central de Minas. From there, they extend to Vale do Rio Doce and Zona da Mata regions, extending to the South of Minas Gerais.

Cluster 2 APAEs, on the other hand, with average effectiveness and efficiency, present greater territorial dispersion, extending across the northern regions: Jequitinhonha,

Mucuri Valley, Northwest and Triângulo Mineiro/Alto Paranaíba, descending to Campo das Vertentes and Sul de Minas. APAEs that, in the opinions of their managers, present better and symmetrical measures of effectiveness and efficiency (clusters 3 and 4) are more concentrated in the Central Mineira region, passing through the metropolitan regions of Belo Horizonte and Campo das Vertentes until they reach the Triângulo Mineiro/Alto Paranaíba and the South of Minas.

Analyzing these clusters, which show symmetry between the measures of effectiveness and efficiency based on the territorial category, we observe that the APAEs in the state's poorest regions (Jequitinhonha and Vale do Mucuri) are located in the average effectiveness and efficiency stratum and not in the lowest stratum. That leads us to consider two possibilities: either the understanding of effectiveness and efficiency is different in these regions, or the systems in which these APAEs are located are less complex, allowing them to achieve greater effectiveness and efficiency measures. The North of Minas, another poor region of the state, also has APAEs with the lowest symmetric measures (low and average effectiveness and efficiency).

The regions of the South of Minas Gerais, Triângulo Mineiro/Alto Paranaíba and Metropolitana de Belo Horizonte also draw our attention. These are more prosperous regions of the state, in which APAEs of all levels of effectiveness and efficiency are located, from the lowest to the highest, showing significant organizational heterogeneity among them in these regions. The regions of Zona da Mata, Central Mineira, Oeste de Minas, Campo das Vertentes and Vale do Rio Doce also present a variety of APAEs with different levels of effectiveness and efficiency. However, they are more concentrated between the low and average strata. The APAEs in the Northwest of Minas Gerais do not show much symmetry between the two effectiveness and efficiency measures, happening in only one of them (average effectiveness and efficiency).

When looking at those clusters that present asymmetries between the two measures of effectiveness and efficiency, we see that they are present in all state regions. However, the regions of the South of Minas; the metropolitan area of Belo Horizonte; North of Minas; Mucuri Valley; the Central part of Minas; West of Minas; Zona da Mata and Triângulo Mineiro/Alto Paranaíba have the majority of APAEs with one of the two measures at the highest stratum. The regions in the Northwest of Minas Gerais and Jequitinhonha have most of the APAEs with one of the measures of effectiveness and efficiency in the lowest stratum. Finally, the regions of Vale do Mucuri and Campo das Vertentes, with one and two APAEs, respectively, present asymmetric levels of effectiveness and efficiency.

Following the configuration of the eight clusters determined by the quartile distribution of the values of the effectiveness and efficiency indices, we sought to relate these indices to the variables considered in the study: three external variables (number of inhabitants per municipality; GDP per capita and estimated population of PWID in the municipality) and two internal variables (number of users and number of employees).

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We started by using the Pearson correlation coefficient, verifying that there is no statistically significant correlation between most external and internal variables and the effectiveness and efficiency indices (Table 6).

Variables	Efficiency index	Effectiveness index
Municipal population	-0.024	-0.063
Municipal gross domestic product per capita	0.096	0.018
Estimated population of people with intellectual disabilities in the municipality	-0.026	-0.064
Number of users per Associações de Pais e Amigos dos Excepcionais	0.117	0.095
Number of employees per Associações de Pais e Amigos dos Excepcionais	0.182*	0.115

Table 6 *Pearson correlation coefficients*

Note. **correlation is significant at the 0.01 level (two ends); *correlation is significant at the 0.05 level (two ends).

Only one internal variable is statistically significantly associated with the efficiency index. The variable "number of employees", whose value of the Pearson correlation coefficient is equal to 0.182, shows a weak association between this variable and the efficiency index. Such correlation value means that the more employees they have, the more efficient the APAE will be. However, the effectiveness and efficiency indices are strongly associated with the value of the correlation coefficient of 0.795, revealing that the greater the effectiveness, the greater the efficiency, and vice versa. That means that the most effective actions tend to be more efficient, and the least effective ones tend to be less efficient.

Despite the results presented above, we decided to advance in the analysis by building two multiple linear regression models, in which the effectiveness and efficiency indices were included as dependent variables and the external and internal variables introduced as independent variables (municipal population; GDP per capita; the estimated population of PWID; the number of users and number of employees). From these models, we observed that the coefficients of determination (R^2) were 0.027 when considering the effectiveness index as a dependent variable, and 0.054 when the dependent variable considered was the efficiency index, that is, in both cases showing that the independent variables explain little or nothing for the variations that occurred in the two indices. Therefore, the independent variables: population of the municipality, GDP per capita of the municipality, estimated population of PWID, the number of users and employees of APAE — are not adequate to explain the variations in the levels of effectiveness and efficiency of the APAEs in Minas Gerais.

The fact that this model has no explanatory capacity raises two issues: either the managers' understanding of the efficiency and effectiveness indices varied a lot, with the APAEs network in Minas Gerais showing different understandings of the questions asked in the questionnaire; or, the understanding and explanation of efficiency and effectiveness models in the Minas Gerais APAEs is based on other, unknown variables that can be qualitative rather than quantitative as the ones used in this study.

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Final Remarks

Regarding the objectives described in their mission, this study's results point to a certain homogeneity among the APAEs in the state of Minas Gerais. As we analyze APAE managers' perception of their mission based on the three dimensions: offering of services, improvement in the quality of life of the PWID, and defending the rights of these individuals, we conclude that the most prevalent dimension in the daily actions of all the APAEs, regardless of their size, is that of improving the quality of life. There is a centrality of these organizations serving the subject with disabilities, with their more significant investment in technical and non-administrative personnel. The low investment in administrative staff may influence the provision of some data by APAEs in the official systems of the Brazilian State as we realized that a significant number of APAEs did not report the number of users served by the existing services.

The present study also points to the need to expand public policy aimed at people with disabilities in the state of Minas Gerais. When we examine the estimated population of people with intellectual disabilities, most of the APAEs care for a percentage below 50% of this population. On the other hand, a significant percentage of waiting lists point to a population without assistance from APAEs or any other service in the municipality. This situation is aggravated by APAEs' difficulty in disengaging people with intellectual disabilities from their services.

Finally, it is worth noting the small participation of users (people with intellectual disabilities and their families) in defining the services provided by APAEs. In addition, it was not possible to draw a quantitative explanatory model that could measure the efficiency and effectiveness of APAEs from Minas Gerais. A qualitative understanding of the systemic dynamics of each cluster should be conducted, highlighting traits that contribute to an accurate, distinct, and coherent "picture" of each of them.

Translation: Laura Mendes Loureiro

References

Almeida, R. A., & Botelho, D. (2006). Construção de questionários. In D. Botelho & D. M. Zouain (Eds.), *Pesquisa quantitativa em administração* (pp. 90–108). Atlas.

APAE Brasil. (2015). *Estatuto das APAEs*. http://200.134.28.17/arquivo.php?arq_id=19579&visualizar=1

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Bériot, D. (1997). *Mudanças na empresa: Uma abordagem sistêmica: Do microscópio ao macroscópio* (A. M. Neves, Trans.). Instituto Piaget. (Original work published 1992)

Brito, S. P. (1989). *A sociologia e a abordagem sistêmica.* Papirus.

Cameron, K. (1986). Effectiveness as paradox: Consensus and conflict in conceptions of organizational effectiveness. *Management Science, 32*(5), 539–553. https://doi.org/10.1287/mnsc.32.5.539

Castro, R. B. (2006). Eficácia, eficiência e efetividade na administração pública. In J. A. G. de Pinho (Ed.), *Anais do 30º Encontro Nacional da Associação Nacional de Pós-Graduação e Pesquisa em Administração* (pp. 1–11). NPGA/UFBA.

Decreto nº 6.949, de 25 de agosto de 2009. http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2009/decreto/d6949.htm

Deliberação CIB/SUS/MG nº 1.404, de 19 de março de 2013 (2013). https://www.saude.mg.gov.br/images/documentos/Del%201404%20-%20Institui%20PIPA.pdf

Deliberação CIB/SUS/MG 1.403, de 19 de março de 2013 (2013). https://www.saude.mg.gov.br/images/documentos/Del%201403%20-%20CASPD%20-%20SERDI-%20Servi%C3%A7o%20especializado%20de%20reabilita%C3%A7%C3%A3o%20em%20Deficiencia%20Intelectual.pdf

Drucker, P. F. (1994). *Administração em organizações sem fins lucrativos: Princípios e práticas* (N. Montingelli Jr., Trans.). Pioneira. (Original work published 1990)

Durand, D. (1992). *A sistémica* (J. L. G. Matos, Trans.). Dinalivro. (Original work published 1979)

Gil, A. C. (2008). *Como elaborar projetos de pesquisa.* Atlas.

Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira. (2020, November 3). *Censo escolar 2020.* https://www.gov.br/inep/pt-br/areas-de-atuacao/pesquisas-estatisticas-e-indicadores/censo-escolar/resultados

Laville, C., & Dionne, J. (1999). *A construção do saber: Manual de metodologia da pesquisa em ciências humanas* (H.Monteiro & F. Settineri, Trans.). Artmed; Editora UFMG. (Original work published 1997)

Lei nº 13.019, de 31 de julho de 2014 (2014). http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2014/lei/l13019.htm

Robalo, A. (1995). Eficácia e eficiência organizacionais. *Revista Portuguesa de Gestão*, (3), 105–116. https://repositorio.iscte-iul.pt/bitstream/10071/1383/5/robalo_RPG_1995.pdf

Rosnay, J. D. (1975). *Le macroscope vers une vision globale.* Èditions du Seuil.

Schalock, R. L., & Verdugo, M. A. (2007). El concepto de cualidad de vida en los servicios y apoyos para personas con discapacidad intelectual. *Revista Española sobre Discapacidad Intelectual, 38*(224), 21–36.

Secretaria Nacional de Assistência Social. (n.d.). *Censo SUAS 2020.* Retrieved July 6, 2021, from http://aplicacoes.mds.gov.br/sagi/snas/vigilancia/index2.php

Steinberg, R., & Powell, W. W. (2006). Introduction. In W. Powell & R. Steinberg (Eds.), *Non-profit sector: A research handbook* (2nd ed., pp. 1–9). Yale University.

Tenório, F. G. (2009). Gestão de ONGs: Principais funções gerenciais (11th ed.). Editora FGV.

Veiga, C. V., Saragoça, J., Fernandes, L. M., Silva, C. A., & Domingues, I. (2014). Teoria e metodologia. In C. V. Veiga & L. M. Fernandes (Eds.), *Inclusão profissional e qualidade de vida* (pp. 9–49). Edições Húmus.

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Thematization of Disability in Children's Literature – Perspectives on the Characters

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Abstract

This study aims to discuss characters with physical disabilities in children's literature. The discussion is relevant once the theme has been placed in books produced for children in Brazil, especially since 2008, with the National Policy for Special Education in the Inclusive Perspective (Decreto nº 6.571, 2008). Although the issue had already appeared in some literary works in earlier periods, usually with a stereotyped approach. Children's literature publishers, faced with various institutional policies and programs, found a lode in the topic of special needs. Undoubtedly, social and political pressures for inclusion interfere in literary productions and their insertion in the school context. In this sense, analysing works that do not reinforce stereotypes or refer to disability as heroic overcoming, resignation and acceptance of fate, placing the characters in conditions of subordination and/or that inspire pity or divine will, can collaborate to broaden perspectives on what it is stigmatised as a disability as well as the limits and possibilities of the human being in different conditions and potential. Comparing children's books that bring these two aspects — overcoming and accepting the real versus resignation and heroic overcoming — may help readers and children to understand the disability as part of normality and open good perspectives for discussion on the subject with these readers under training.

Keywords

physical disability, children's literature, inclusion, text comprehension

Tematização da Deficiência na Literatura Infantil — Olhares Sobre as Personagens

Resumo

O presente estudo se propõe a problematizar a representação de personagens com deficiência física em obras de literatura infantil. A discussão é relevante visto que a temática vem se colocando em livros produzidos para a infância no Brasil, principalmente a partir de 2008, com a Política Nacional de Educação Especial na Perspectiva Inclusiva (Decreto nº 6.571, 2008). Embora a questão já aparecesse em algumas obras literárias em períodos anteriores, geralmente com uma abordagem estereotipada. As editoras de literatura infantil, diante de várias políticas e programas institucionais, acharam um filão no tema das necessidades especiais. Indubitavelmente, pressões sociais e políticas de inclusão interferem nas produções literárias e sua inserção também no contexto escolar. Neste sentido, analisar obras que não reforcem estereótipos ou remetam a deficiência como superação heroica, resignação e aceitação do destino, colocando

as personagens em condições de subalternidade e/ou que inspirem piedade ou vontade divina, pode colaborar para a ampliação de olhares acerca do que é estigmatizado como deficiência e os limites e possibilidades do ser humano em diferentes condições e potencialidades. Comparar livros infantis que trazem esses dois aspectos — superação e aceitação do real versus resignação e superação heroica — pode ajudar leitores e crianças a compreender a deficiência dentro de uma normalidade e abrir boas perspectivas de discussão sobre a temática com esses leitores em formação.

Palavras-chave

deficiência física, literatura infantil, inclusão, compreensão textual

Introduction

Literacy knowledge is essential for the development of children and young people. When we talk about experiences with literary texts, we show literature that is an art and, according to Coelho (2000), is synonymous with creativity that represents the world, humans, life through words. Children's contact with literary texts can benefit their understanding of the world, ensuring that the literature adequately reflects the diversity of their experiences, as well as a sense of belonging to a social and real environment.

Price et al. (2016) reinforce that activities such as reading an infant literary text help build the reader's vocabulary, oral language, and communication skills. From this perspective, Sonnenschein and Munsterman (2002) claim that it impacts literacy and vocabulary acquisition, supports other areas of development, such as children's personal, social, and emotional features. Furthermore, we understand that reading infant literature allows children to learn new things about the world, remember events they already know, and relate their personal experiences to facts or episodes depicted in the books. In the same way, these young readers can learn about relationships and discuss diversity and differences.

For this to happen, the book market is full of books with different materials, genres, and themes that seduce children and young people.

Regarding materiality, some books are rich in covers and paratexts, showing the reader little secrets of the work, ensuring reader interaction. Souza and Bortolanza (2012) argue that the book "fulfils its irreplaceable and indispensable humanising function for the integral development of its personality" (p. 69), referring to the personality of the infant reader.

Another issue that can attract reading is the textual diversity that we can find on the shelves of bookstores, schools and public libraries. Texts and speeches can be perceived from the uses and functions they acquire in communicative situations. According to Machado (2014), contemporary children's literature was inspired by various sources of the literary tradition, including oral ones and, therefore, the importance of identifying them.

> Once children's literature is the adjective that specifies its addressing, it
> was taken as a "genre" for a long time, which, in a sense, concealed the

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> heterogeneity of genres that constituted it. (...) texts that we call "infant literature "have a wide range of literary genres that confirm this heterogeneity: fables, poems, short stories, legends, among others. (Machado, 2014, n.p.)

Approaches to literature for children and young people are varied and depend a lot on when the texts were written; that is, there is a thematic relationship with the political and social history of the country where the work was released. In Brazil, for example, the first writings for infant readers, produced at the end of the 19th century and beginning of the 20th century, had as their theme a sense of pride and the ideal child — the well-behaved, quiet, educated one. After that, Monteiro Lobato (1882–1948) inserted themes closer to childhood and placed children's characters at the centre of his texts.

Nowadays, we find infant literature on any subject. Paiva (2008) mentions "reality as a bet" of the publishing market, that is, books that portray themes such as death, fear, separation, racial issues, feelings — subjects considered both delicate and controversial issues. According to the author, texts that explore this thematic axis take advantage of the contexts and scenarios of children's daily life, allowing them to see themselves in history by associating their experiences with the plot, thus using their prior knowledge but still expanding the possibilities of understanding and meaning of the world, of others and themselves.

In this same theoretical perspective, Kirchof et al. (2013) notice that "in Brazil, since the mid-1990s, but especially in the 2000s, the growth of interest in themes related to differences have become noticeable in the broader social scenario, with consequences also in a wide range of productions addressed to children" (p. 1045).

Thus, children's literature starts to thematise race, ethnicity, age, disability, sexual orientation, body conformation, and gender differences.

In this article, we will address physical disability and how characters with disabilities are represented in some works aimed at children.

Inclusion and Disability — Brief History of Legal Frameworks

In the history of people with disabilities, there is a long way for society to respect them and include them in social, educational and political contexts. Inclusion is understood by Freire (2008) as an educational, social and political movement supporting the right of all individuals to participate, consciously and responsibly in the society they belong to and to be accepted and respected in their difference (p. 5). In the educational context, it also defends the right of all students to develop and realise their potential and adjust the skills that allow them to exercise their right to citizenship through quality education, designed to account for their needs, interests and characteristics (Freire, 2008, p. 5).

Thus, the concept advocates the universalisation of human rights, emerging as a guiding perspective for public policies. We have been interested in showing some international actions aimed at including people with disabilities. To do so, we draw a short history of the legal frameworks regarding inclusive education.

In Brazil, the Federal Constitution establishes equality as a right:

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> Education, a right of all and a duty of the State and the family, will be promoted and encouraged with the collaboration of society, aiming at the full development of the person, his/her preparation for the exercise of citizenship and qualification for work. (Constituição da República Federativa do Brasil art. 205)

Among its educational principles, the equality of conditions for access and permanence in school is explained in Article 206, Subsection I (Constituição da República Federativa do Brasil art. 206, §I). In contrast, specialised educational assistance for students with disabilities is mentioned in Article 208, Subsection III, as an obligation of the State which must preferably be carried out in the regular educational system (Constituição da República Federativa do Brasil art. 208, §III).

In 2010, through Constitutional Amendment no. 65, Article 227 was redrafted, placing the fight against discrimination and promoting equality as a duty of all. In that same article, among its commandments, it reads:

> II - the creation of prevention and specialised care programs for people with physical, sensory or mental disabilities, as well as the social integration of adolescents and young people with disabilities, through professional training and coexistence, provide access to collective goods and services, with the elimination of architectural obstacles and all forms of discrimination. (Emenda Constitucional n° 65, 2010, Art. 227, §II)

There have also been, throughout the world, movements to combat social exclusion and high levels of illiteracy. In this direction, under the coordination of the United Nations Educational, Scientific and Cultural Organization (Unesco), were held conferences and conventions from which essential documents have been published.

In Brazil, based on the Federal Constitution and international declarations, Ministry of Education Ordinance no. 1.793 was published, which recommended, in its Article 1, the "inclusion of the subject' Ethical-political-educational aspects of normalisation and integration of person with special needs', primarily in the courses of Pedagogy, Psychology and in all Degree Courses" (Portaria n° 1.793, 1994). It is important to emphasise that most of the degree courses mentioned did not meet this recommendation for various reasons this article will not address.

In December of 1996, Law no. 9.394 — Law of Guidelines and Bases of National Education (Lei n° 9.394, 1996) entered into force, which, in Chapter V, deals specifically with special education, which is understood as a "modality of school education offered preferentially in the regular network of teaching, for students with disabilities, pervasive developmental disorders and high abilities or highly gifted ones" (Art. 58).

Decree no. 3.298 (Decreto n° 3.298, 1999) states that "any loss or abnormality of a psychological, physiological or anatomical structure or function that generates incapacity to perform an activity, within the standard considered normal for human beings" (Art. 3, §1). That impacted the school environment because, by force of law, it began to compel

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educational systems (public and private) to receive students who sought the institution to enrol themselves. There was a reaction from professionals who argued that they had not been prepared to work with this "new" student profile. Moreover, the "inclusion" was carried out without providing most establishments with infrastructure, equipment, accessibility and other basic needs for the reception of students who required/require specialised care.

In line with this policy, in 2001, the National Guidelines for Special Education in Basic Education were published through Resolution CNE/CEB no. 2 (Resolução CNE/CEB nº 2, 2001). It states that education systems must enrol all students, making schools responsible for organising the care procedures for those with special educational needs, ensuring the necessary conditions for quality education.

Hence, it sets as a principle to value and recognise the potentials and differences of people with disabilities, seeking, in the training and guidance of education professionals, to offer paths for inclusion, even though more in legal terms than concrete viability of conditions of access and permanence of those who needed/need specialised and personalised care.

In 2008, it was the National Policy for Special Education from the Perspective of Inclusive Education whose objective was: "to ensure the school inclusion of students with disabilities, pervasive developmental disorders and highly skilled/gifted ones, guiding education systems to ensure: access to regular education, with participation, learning and continuity at the highest levels of education" (Decreto nº 6.571, 2008, p. 14). In July, Legislative Decree no. 186 (Decreto Legislativo nº 186, 2008) approved the text of the International Convention on the Rights of Persons with Disabilities and the optional protocol, signed in New York (30/03/2007). The decree provides the following definition of discrimination:

> discrimination on the grounds of disability means any differentiation, exclusion or restriction based on disabilities, with the purpose or effect of preventing or precluding recognition, enjoyment or exercising under equal opportunities as other people, as well as jeopardising all human rights and fundamental dues at political, economical, social, cultural, civil or any other field. It comprises all forms of discrimination, even the refusal of reasonable adaptation. (Decreto Legislativo nº 186, 2008, Art. 2)

Amongst the fundamental points against the prejudice of any and all forms of discrimination, several actions impacted the production of materials aimed at this segment. An example can be seen in the research by Barros (2015), who surveyed 150 children's books published from the 1970s to 2010 in Brazil, which depicted disability (Figure 1).

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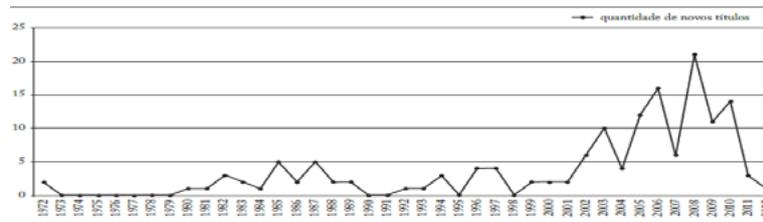
Figure 1 *Children's books depicting disability versus year of first edition publishing.*

Source. From "Quarenta Anos Retratando a Deficiência: Enquadres e Enfoques da Literatura Infantojuvenil Brasileira"
(Forty Years Picturing Disability: Framings and Approaches to Brazilian Children's Literature), by A. S. Barros, 2015,
Revista Brasileira de Educação, 20(60), p. 171 (https://doi.org/10.1590/S1413-24782015206009). CC BY-NC.

The graph corroborates the argument that, despite some previous indications, notably from 2003, we have seen affirmative and inclusive actions in more significant numbers with the establishment of social and economic policies. The impact on editorial production is an example of this. A possible reason for the decrease from 2008 is that the Ministry of Education stopped buying books for Brazilian public schools, which has happened since 2013.

Given the scenario, in 2014, the National Education Plan (PNE 2014/2024) was approved, comprising 20 goals and strategies, specifically aimed at special education:

> universalise, for people from 4 to 17 years old who present disabilities, pervasive developmental disorders, and highly skilled and gifted individuals, access to basic education and specialised educational care, preferably in the regular educational system. Besides, provide an inclusive educational system, multifunctional resources room, classes, schools, or specialised services either public or affiliated. (Lei nº 13.005, 2014, p. 55)

In 2015, the Brazilian Law of Inclusion of Persons with Disabilities (Statute of Persons with Disabilities; Lei nº 13.146, 2015) was approved, based on the International Convention on the Rights of Persons with Disabilities, which must be inclusive and of quality in all educational levels; guarantee conditions of access, permanence, participation and learning, through the provision of accessibility services and resources.

Over the period we have presented as a time frame (1988–2018), it is possible to observe changes in legislation and enhancement of laws, plans and actions aimed at inclusive education. It is necessary to point out that the international declarations and reports were and are essential in strengthening it to guarantee the rights of people with disabilities and fight prejudice and discrimination.

These very rights must be expressed in literary books meant for children as long as we assume that literature forms the subject to respect differences and understand them. Thus, it is essential to verify how such characters are represented in literature for children and young people.

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CHARACTERS WITH PHYSICAL DISABILITIES AND CHILDREN'S LITERATURE

We have already stated that children's literature can help the reader's development. According to Price et al. (2016), it can provide a context for understanding social norms and behaviours, helping children learn how to adapt to society, and facilitating the development of socio-emotional skills. Furthermore, children can obtain information from texts, learn how to link words and images, and understand perspectives that may differ from their own (Sipe, 2012). It is important to notice that literature is the main way children "see the world" (Flynn, 2001). Children's books are a powerful means to promote children's identity and understanding of several cultures, and literature can also lead its readers to understand and accept individuals who are different (Adomat, 2014). Sensitive or controversial issues in children's literature books have taken up much academic research in several countries. Discussions on the depiction of gender, body size, individuals from different cultures and linguistic communities and individuals with disabilities are recurrent in children's books (Price et al., 2016).

According to the authors (Price et al., 2016), such issues began to be inserted in children's literature and analysed with more emphasis from the 21st century onwards. Although characters with disabilities have been the main characters in narratives in several countries since the 19th century, few empirical studies focus on how characters with disabilities are portrayed in children's books (Prater, 1999).

Dowker's (2013) study analyses characters with disabilities. The results showed that these characters are often depicted as limited in personality and lacking depth. According to Price et al. (2016), "the representations of characters with disabilities in these storybooks were largely inaccurate. For example, protagonists with disabilities were often portrayed as having received miraculous cures" (p. 564). Empirical studies have also examined how specific deficiencies are portrayed in literature. For example, children with intellectual impairment were mainly presented in supporting roles rather than as main characters (Prater, 1999).

Studies, especially English ones, show that, from 1990 and early 2000, there has been a positive trend in identifying characters with disabilities, as they appear in more inclusive settings. Price et al. (2016) claim that "in these books, characters with disabilities engage in typical everyday activities, including positive and meaningful interactions with their peers, their disabilities are not the focus of the story" (p. 564). Researchers (Dyches & Prater, 2005) have found that children with intellectual disabilities are often portrayed in supporting roles or as "protectors", and their impairments are not pointed out.

However, although such research brings out results beyond stereotypes regarding physical disability, there is still a shortage of children's books, whether English, North American, Portuguese or Brazilian, that positively depict characters with such disabilities.

In light of the above, it is essential to emphasise that in Brazil, according to Kirchof et al. (2013), "important research centres on children's literature that in recent years,

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"important research centres on children's literature discuss the issue of differences have been created" (p. 1048). One of these groups, Curriculum, Culture and Society Studies Nucleus (NECCSO) — coordinated by Rosa Maria Hessel Silveira, has collected children's books whose theme is the difference. The list made by NECCSO from 2013 to 2016 has more than 700 titles that cover issues such as deafness, fatness, blindness, wheelchair users, death, gender and sexuality, the elderly, and others.

When we surveyed the texts that bring wheelchair users and people with physical disabilities, we found in the NECCSO titles only 29 works, including translations from Europe and North America. This reduced number of books only reinforces what scholars have affirmed in the research exposed.

To analyse children's books, we sought the criteria and representations of disability based on a discussion prepared by North American researchers (Price et al., 2016), who observed the works as specific quality entities of disabilities depicted in the books.

Quicke (1985) emphasises the importance of representing characters' physical appearance and behaviour by creating a generally optimistic tone through stories that reflect realism (Dyches & Prater, 2005). Characterisation, relationships with other characters, the level at which characters grow and transform, and characteristics of good practice in the field of special education form the basis for further analysis (Altieri, 2008; Dyches & Prater, 2005).

Altieri (2008) and other researchers (Price et al., 2016; Quicke, 1985) state that, when selecting a book, it is vital to question the terminology used in the disability descriptions and whether the character's disability is quickly resolved or explained as an ongoing challenge. Furthermore, the researchers suggest verifying power dynamics in the relationships between the characters and who works as a "hero" in each story (Curwood, 2013).

Although each researcher presents specific ideas and focuses on literary topics, we can reach a consensus on what separates a positive picture of disability from an unfavourable one. Texts that contain stereotypes of representations of disability are rated as "inappropriate" (Beckett et al., 2010). According to the cultural model of disability, negative portrayals can also emphasise biological barriers to disability.

According to Beckett et al. (2010), characters are victimised, dependent, or objects of pity and, in this sense, the critical reader can consider the several character profiles with disabilities. The critical reader must then consider the role of the character with a disability in negative portraits. They can also serve just as examples of perseverance. The propensity of characters to act as leaders, problem-solvers, role models, and heroes continually relegate those with disabilities to inferiority (Hughes, 2012).

Another common feature of negative portraits is that characters with disabilities are granted almost superhuman attributes in an apparent attempt to compensate for their deficiencies (Yenika-Agbaw, 2011). Several professionals also agree that it is inappropriate for a character with a disability to be restored through a miracle cure (Dowker, 2013).

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In addition to listing the story elements that form negative representations of disability, the researchers (Beckett et al., 2010) named features that contribute to positive characterisations. The most outstanding quality of characters is complexity; characters must have the dignity of depth and the freedom to evolve. In positive portrayals, characters with disabilities are depicted as individuals with unique personalities and interests (Hughes, 2012), and they are not disability-determined (Beckett et al., 2010). Researchers insist that children's books about disabilities must be realistic to be acceptable (Beckett et al., 2010).

Many researchers also value the quality and accuracy of illustrations, so images of characters with disabilities must be free from stereotypes and bear positive physical descriptions in the text (Wopperer, 2011). Characters with disabilities must play various roles, serving as leaders, problem solvers, supporters, and heroes (Dyches & Prater, 2005; Wopperer, 2011). Texts showing positive characterisations present characters with independent disabilities, making choices and demonstrating self-determination. Stories must portray the appropriate inclusion of these subjects in society; they need to be given all the rights of citizens and find attitudes of acceptance by other characters and the community.

Considering the purpose of this article — to present some characters with disabilities and figure out how they are portrayed — we also provide below some criteria that helped us build a framework with guidelines for the analysis (Table 1).

CRITERIA	DEFINITIONS
Stereotype	Identify if there are stereotypes about characters with disabilities in illustrations and narratives
Type of action of characters	Analyse if characters with disabilities are presented in leading and action roles in illustrations and narratives; if they are depicted as "practitioners" or "observers"
Acceptance of individual behaviour	Verify if books present characters who are accepted by their behaviour
Problem-solving	Identify if characters with disabilities are involved in the problem-solving of narrative conflicts
Possibility of telling the same story	Certify that the same story could be told if its characters did not have any disability
Other characters as positive models	Verify the presence of a character with or without a disability with whom a child with disabilities could feel identified as a positive and constructive model

Table 1 *Definitions and criteria of analysis*

Source. Adaptation of Price et al., 2016

Disability and Its representations

When we recall a character in Brazilian children's literature who was presented with a physical disability, we immediately think of *O Patinho Aleijado (*The Crippled Duckling; Pimentel, 1952), a compilation and adaptation by Figueiredo Pimentel for Andersen's tale *The Ugly Duckling*. In this *Brazilianization* of the Danish short story, an elaborate language distances itself from the real reader with clear intentions of nationalising the European collection (Zilberman & Lajolo, 1993).

The tale tells the story of an old duck that hatched some eggs after the ducklings were born, "all that was missing was the big egg, which, however, had no sign of being hatched" (Pimentel, 1952, as cited in Zilberman & Lajolo, 1993, p. 25). Although the other ducklings *asserted* that that egg must be from another animal and that this one is born and growing could eat the ducklings, the mother duck did not abandon the nest.

> Seven days after the last duck came out, the old duck saw the big hatched egg, and an animal appeared, looking like a duck. It is true, but all crooked, dark and crippled.
>
> Soon mother duck regretted having hatched such an ugly animal. But, as it had a good heart, and not wanting to let it go, showing her annoyance at disgraceful, disgusting duckling in its brood, the mother said nothing to her peers. (Pimentel, 1952, as cited in Zilberman & Lajolo, 1993, p. 26)

In addition to the duckling's physical disability, the text shows in its outcome that, since its birth, it has suffered from "kidding, teasing, teasing, booing by every feathering gang" (Pimentel, 1952, as cited in Zilberman & Lajolo, 1993, p. 26). We could say that, as early as 1896, the character was bullied. In this story, physical disability is treated with prejudice, even by the mother duck, who "began to hate the cripple" (p. 26) because the duck community rejects its son.

However, the "crippled" character does not have the same attributes Andersen's *The Ugly Duckling* has, but Pimentel ends the narrative by highlighting one quality of the character that could swim better than everyone else. In other words, although it stood out for swimming well, it probably lived alone, as it was not accepted by the band that rejected it. There are also signs of prejudice when the author attributes the "dark" colour and the "crooked" characteristic to the duckling.

Thus, we agree with Dowker (2013) when stating that "the way disability was represented in 19th-century fiction is quite complex. Some characters are portrayed flatly, as villains or, more often, as pitiful characters" (p. 1054). And, this is the case of *O Patinho Aleijado* (Pimentel, 1952).

We ask next is whether the depiction of characters in the 21st century has changed. How are characters with physical disabilities portrayed in contemporary Brazilian children's literature?

To do so, we review six books, five of which are on the NECCSO list, and only one of them is not on that list. However, regardless of their aesthetic quality, all of them were found in a children's school library. The works were selected following only one parameter: having their first edition from 2000, produced and edited in the 21st century (Table 2).

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Title	Author	Illustrator	Publisher	Year
Conquista Futebol Clube (Conquest Football Club)	Telma Guimarães Castro Andrade	Fê	Editora do Brasil	2006
O Giro da Bailarina (The Ballerina's Spin)	Keyla Ferrari Lopes	Dimaz Restivo	Paulinas	2008
Caminhando com Paulo (Walking With Paulo)	Sharlene Serra	Ricardo Pontes	Not mentioned	2010
O Grande Dia (The Great Day)	Patrícia Secco	Daniel Kondo	Melhoramentos	2011
Igual e Diferente (Equal and Different)	Arlene Holanda	Arlene Holanda	Expressão Gráfica e Editora	2011
Meu Irmão Não Anda, mas Sabe Voar (My Brother Doesn't Walk, but He Knows How to Fly!)	Angel Barcelos	Manoel Veiga	Gutenberg	2013

Table 2 *Books surveyed*

Amongst these children's books, the only title that plays an explicit pedagogical role is *Caminhando com Paulo* (2010), as the wheelchair character is the motto of a material that teaches about accessibility. In the book, a third-person narrator highlights several problems faced by Paulo as a wheelchair user: sidewalks without ramps, places with stairs, cars parked in places for people with disabilities, narrow doors in movie theatres, restrooms without handrails, among others.

In this sense, there is a mismatch between the verbal and the visual text since illustrations only repeat what the text says. For example:

> I was outraged by the situation of Paulo and others with reduced mobility. The next day I called a group of friends. Together we organised a mobilisation: posters, banners and speeches. We want to draw attention to the issue of accessibility in our city.

The double-page images show three wheelchair users in the foreground, one of them is Paulo, and several people holding posters and banners, with facial expressions of anger and revolt.

The narrative ends with Paulo happy, celebrating with friends since accessibility has improved in his city. Moreover, in Paulo's words, now the subject of the speech: "this proves that together we can make changes and avoid any kind of discrimination". The book also brings pages with activities on accessibility for readers to prove what they have learned: "walking with Paulo – an activity for students" and some articles from the Convention on the Rights of Persons with Disabilities presented in the last two pages of this book.

We perceive the role of Paulo, just as a character used to publicise the daily problems of people with physical disabilities who live in cities not planned for them. Paulo is not the protagonist, the third voice of the narrative, a poorly prepared narrator, as the reader does not know who he is but realises that he takes pity on the wheelchair user and decides to help him. There is, therefore, an explicit function in showing accessibility problems and an attempt to make the reader aware of these problems.

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Regarding the criteria listed in Table 1, we could say that Paulo is a stereotyped character. However, he does not play a leadership role, and neither is he the one who solves the problem of accessibility in the city where he lives. We also believe that the story could not be narrated if the character did not have a physical disability. Although Paulo is a supporting actor, his problems with accessibility make the book *Caminhando com Paulo* possible.

In *Igual e Diferente* (2011), with illustrations and text by Arlene Holanda, the wheelchair-bound character plays a supporting role in poetic prose in which several children with differences are presented. Such differences do not stand out in the book's opening pages by the verbal text, but by the visual, as the first girl (pp. 2–3) is dark and the second (pp. 4–5) is black. In a context of visibility, the differences in this children's book work are marked by illustrations, which show traits of nationality, ethnicity, race, and various deficiencies: deafness, physicality, and muteness. These statements are only expressed in the verbal text from page 8 on, precisely in the middle of the book.

> Clara black skin/ And curly hair/ Diego has fair skin/ And very smooth hair/
> Everybody has beauty/ Each one in a particular way. Tati needs help/ So that
> she can walk/ João has difficulties/ To speak and listen/ They all like care /
> Kisses, hugs. (pp. 8–11)

The book distinguishes itself from *Caminhando com Paulo* for mentioning morality only on the last page: "Everyone has the right/ to health and protection/ to be able to thrive/ without any complications/ and it is good that every adult/ do not forget this lesson!" (pp. 14–15). Therefore, there is a message intended to alert adults to the rights of one's differences. How Arlene Holanda does this in *Igual e Diferente* is, in the words of Kirchof et al. (2013), with a

> "politically correct" bias [which] has invaded a large part of children's literary books, especially in recent years, when the literary narratives have been taken as a vehicle to spread information, to establish moral rules and prescriptions on how to act with this or that difference. (p. 1048)

We cannot say that these two books are from children's literature because although this presents verbal and visual processes modalities, the works analysed so far do not offer children ample possibilities to make sense of what they read, as, after all, the understandings are ready (Cadermatori, 2006).

O Giro da Bailarina (2008) tells the experience of Ana Carina, a quadriplegic girl, with ballet. The narrative is composed in the first person, the protagonist is not stereotyped, and the story does not show a problem. Ana Carina describes how she started dancing and how she likes to perform on stage with joy and a feeling of overcoming. "Hi, I am Ana Carina, and I'm ten years old. I'm here to talk a bit about what I'm feeling.

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You know, I've just gotten off stage, I performed my first ballet presentation. It was like a dream" (pp. 1–2); "I couldn't imagine I was able to make such slight movements that only ballerinas could. Even so, I got very happy" (p. 8).

In the book, the illustrations dialogue with the written text, expanding its meaning possibilities, since the girl subtly exposes her limitations but does not make them explicit, the reader is led by Ana Carina's relationship with ballet to page 15, when the girl dances sitting in a wheelchair.

As it is a descriptive text in the protagonist's voice, Ana Carina is represented as a "practitioner" character, as she is the one who dances with the teacher, the clown and her friends. There are also indications that others accept the character for her behaviour, the reader verifies that in her relationship with the teacher, "I felt like a dancer. My teacher smiled" (p. 5) and with her friends "I have other friends who, like me, also spin on wheels" (p. 20).

The characters — Ana Carina, teacher, friends — are therefore placed as positive and constructive models, and on the one hand, the protagonist and her friends, who are also wheelchair users, are happy, overcome difficulties, and the teacher accepts the differences.

In this aspect, we perceive a sense of equity, according to Cury (2005), a fundamental principle of inclusion, once the verbal text and the characters are not treated in a discriminatory way, and there is an explicit acceptance of their limitations as wheelchair users.

Likewise, in *O Grande Dia* (2011), by Patrícia Secco, Rodrigo is not mentioned as a person with a physical disability. The reader figures this simply by seeing the visual text on the last page. The plot is narrated by Rodrigo, a 12-year-old boy, who tells how he became the football coach for the school team.

The narrative shows the protagonist's skill with games and strategies. Without mentioning that he has a physical disability, the reader cannot infer it through the verbal aspect only: "and as I could not run nor had anyone to play chess with, I was going to watch the football game". The illustrations throughout the book always depict Rodrigo behind a small square one can understand is the back of a wheelchair.

The protagonist in this book is not shown to overcome his disability, as is the case with Ana Carina in *The Ballerina Spin*, but his perception of the problems with the football team leads him to the position of coach. The narrative presents the events sequentially, as after Rodrigo watched the game during the school break, he reports the problems to the team: "my friends were very disorganised, they looked like 11 boys playing alone – chasing the ball, each for oneself! Nothing to do with a game! Nobody passed the ball", and he is, then, included in the group as the coach.

The character is valued for his observational skills and strategy, which places the team in the football championship final: The appreciation of teamwork and respect for people. The text ends in Rodrigo's voice: "and how wonderful it is to know that, even

without being able to run after a ball, my participation was decisive for us to be in this final!". The image that comes with the verbal text is similar to those photographs taken at the beginning of the games when the team joins in two rows and lands for the official club photo. Thus, three boys hug and stand in front of them, two squat and Rodrigo sits in his wheelchair, holding the soccer ball.

In this aspect, Rodrigo's inclusion in the group is different from the stories analysed in previous books. We believe that the character does not have a stereotype and that the narrative's performance represents leadership. Therefore, Rodrigo is a practitioner character, he is the one who solves the narrative problem, and the group accepts him for his individual behaviour. He is shown as a positive role model, as his physical disability does not prevent the story from being told. Daniel Kondo's illustrations play a significant role because, in addition to dialoguing with the verbal text, they mobilise the reader to perceive meanings that can provide an autonomous reading experience.

The theme of football is brought again in *Conquista Futebol Clube* (2006), by Telma Guimarães. The 32 pages book tells the story of Davi since his birth, and the paediatrician informs the boy's parents that he was born with a malformation in the backbone. In the initial conversation between Davi's parents and the physician, two pieces of information move the narrative: the importance of the stimulus to perform all activities; and the search for ways to carry out various tasks.

Davi's relationship with his parents and older brother, Felipe, is seen by their coexistence, by the search for a solution to small impasses, such as a sink in the bathroom the boy's height. It is at school that major problems will be presented: difficulty in enrolling him in the same school as his brother because the school does not have any people with disabilities; accessibility problems and, finally, the acceptance of the disability by the other children in the classroom.

Davi's great conflict, in the third-person narrative, is the fact that he cannot play football in physical education classes. To resolve the issue, he begins, secretly from the family, to build a wooden leg with a trainer at the end, which allows him to kick the ball. To test his invention, he needs a football team, and at this point, Davi observes other classmates and realises they don't take part in the class either because one is obese, the other wears glasses, and so forth. The boy's team is made up of several children who, one way or the other, felt excluded, either for being different or for bullying.

Davi then forms his team — Conquest Football Club — and the children start training on Saturdays. Felipe, his brother, plays the role of referee, and the team draws the attention of the principal and other students at the school. As an outcome, the school management prepares the school with ramps, accessible restrooms and accepts other students with disabilities; the children of the team are recognised by the other students in the school, who feel like playing soccer with them.

In *Conquista Futebol Clube*, the visual text has verbal text, reproducing the narrative's events in images. For example, in the episode where Davi talks to the girl from the

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canteen, he suggests putting up a list of the day's meals because he could not see the counter. The illustration on the right side of the page takes half the space vertically, and the reader can see a very tall cafeteria, with the girl at the counter and Davi with his head and arms raised, not seeing the canteen's interior.

The protagonist and his family are not identified as stereotyped. However, the characters that appear and form the team are. Mathias, the obese boy, is called "Cork"; João, the boy with glasses, known as "Eye"; Robervaldo and Giovaneusa were excluded because of their strange names. The linguistic resources used to portray these characters' features do not escape worn out stereotypes; however, some readers may identify with these bullying problems, all too common in schools.

Davi plays a leadership role and accepts his physical condition, looking for ways to play soccer, thus fulfilling a desire, he is accepted by the group, so there would be no possibility of telling this story without showing the boy's disability. Therefore, other children with disabilities may find themselves in Davi, who is shown as a positive and constructive role model.

As such, the characteristics found in *O Grande Dia* and *Conquista Futebol Clube* differ from the claims made by Price et al. (2016), who state that, in exploratory research with 102 North American children's books, characters with disabilities did not often have active roles in problem-solving nor was there a fair balance between the roles played by characters with and without disabilities.

In the last book, *Meu Irmão Não Anda, mas Sabe Voar!*, the first-person narrative tells the story of a girl who one day asked her mother for a little brother because she felt so lonely.

> So, on my seventh birthday, I got the best gift in the world: Mom said my little brother was on his way. I found it very strange because her belly 'wasn't even big! How come, then, my brother was about to arrive? It was even stranger When he arrived. It 'wasn't a baby, it 'wasn't small, it was bigger than me! And 'couldn't walk! (pp. 9–15)

This story discusses the friendship between the girl, who has no name, and João, her brother, going through secondary experiences such as adoption and physical disability. The narrator justifies the fact that her brother cannot walk by saying, "but I found he can fly!" (p. 16). This flight has two meanings: the first, related to the speed he can give his wheelchair; and the second, an imaginary flight, described by the girl as: "he says it is at this time that he goes the farthest" (p. 18). The verbal text allows inferences about this moment as the one in which João imagines himself without the physical disability. However, there is a break in expectation on the next page when the "journey" takes the siblings to imaginary worlds of fairies, goblins and talking animals.

We could say that, although this magic remains in the boy's "dream", there is in the representation of this character a return to the 19th century when, according to Dowker

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(2013), "his creative gifts, associated to his emotional sensitivity, are more outstanding than its shortcomings" (p. 1060).

João, the narrator's brother in *Meu Irmão Não Anda, mas Sabe Voar!* is not presented in a stereotyped way. He is a dynamic character, accepted by his sister, in a narrative that does not show a conflict but uses the subterfuge of the creative imagination to accept his limitations.

Final Words

The purpose of this article was to problematise the representation of characters with physical disabilities in children's literature. We brought to the discussion, besides the theoretical assumptions the books analysed and the current legislation regarding inclusive education, also known as special.

According to the 2010 demographic census carried out by the Brazilian Institute of Geography and Statistics (Instituto Brasileiro de Geografia e Estatística, 2012), Brazil has 45,606,048 people with some type of disability, 23.90% of the population. These Brazilians are coming out of the invisibility to which they were relegated for many years and, along with family members, teachers, researchers, writers and other people committed to the cause, they are struggling so that they are not only seen and recognised as people of rights but also fighting stereotypes, stigmatisations and all forms of prejudice.

Thereupon, the issue of inclusive education and the rights of people with disabilities has been enhanced in research, legislation, and the production of children's books in Brazil, both in literary, educational, and other works. Mainly from 2008 on, with the National Policy for Special Education in the Inclusive Perspective, bibliographic production on this subject has increased, although the issue had already arisen in some works aimed at children in previous periods. The six books analysed here date from 2006 to 2013 and present, as discussed in the previous item, different approaches towards disability.

There is no doubt that social and political pressures for inclusion interfere in literary production and its insertion in the school context. Recently, Brazil was faced with a controversy involving the minister of education, Milton Ribeiro, who stated on social media that there are children with "a degree of disability that is impossible to live with" (Alves, 2021), hindering the learning of others students. His statement was the target of much criticism from all segments of society, which made Milton Ribeiro back down and apologise to the population. This fact highlights the lack of information of many Brazilians about disability and inclusion. That would be one more reason for publishers to produce children's books on the subject and, along with parents and teachers, to develop information and clarification campaigns so that children's literature with characters with disabilities may be in the classrooms and discussed among school managers, students and teachers.

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Hence, it is relevant to analyse works that neither reinforce stereotypes placing the characters in conditions of subordination and/or inspiring pity, nor refer to disability as heroic overcoming, resignation and acceptance of destiny or divine will. Therefore, by problematising the representation of characters with physical disabilities in texts aimed at the infant reader, we hope to have contributed to the expansion of perspectives on what is stigmatised as disability and the limits and possibilities of human beings in different conditions and potentialities

Translation: Márcio César Cardoso

References

Adomat, D. S. (2014). Exploring issues of disability in children's literature discussions. *Disability Studies Quarterly*, *34*(3), 1–15. https://doi.org/10.18061/dsq.v34i3.3865

Altieri, J. L. (2008). Fictional characters with dyslexia: What are we seeing in books? *Journal of Literary & Cultural Disability Studies*, *41*(1), 48–54. https://doi.org/10.1177/004005990804100106

Alves, P. (2021, August 19). *Ministro da Educação diz que a crianças com grau de deficiência que 'é impossível a convivência'*. Globo. https://g1.globo.com/pe/pernambuco/noticia/2021/08/19/ministro-da-educacao-criancas-impossivel-convivencia.ghtml

Barros, A. S. (2015). Quarenta anos retratando a deficiência: Enquadres e enfoques da literatura infantojuvenil brasileira. *Revista Brasileira de Educação*, *20*(60), 167–193. https://doi.org/10.1590/S1413-24782015206009

Beckett, A., Ellison, N., Barrett, S., & Shah, S. (2010). 'Away with the fairies?' Disability within primary-age children's literature. *Disability & Society*, *25*(3), 373–38. https://doi.org/10.1080/09687591003701355

Cadermatori, L. (2006). *O que é literatura infantil*. Brasiliense.

Coelho, N. N. (2000). *Literatura infantil: Teoria, análise, didática*. Moderna.

Constituição da República Federativa do Brasil de 1988. art. 205.

Constituição da República Federativa do Brasil de 1988. art. 208, §III.

Constituição da República Federativa do Brasil de 1988. art. 206, §I.

Curwood, J. S. (2013). Redefining normal: A critical analysis of (dis)ability in young adult literature. *Children's Literature in Education: An International Quarterly*, *44*(1), 15–28. https://doi.org/10.1007/s10583-012-9177-0

Cury, C. R. J. (2005). *Os fora de série na escola*. Armazém do Ipê.

Decreto Legislativo nº 186, de 2008 (2008). http://www.planalto.gov.br/ccivil_03/Congresso/DLG/DLG-186-2008.htm

Decreto nº 6.571, de 17 de setembro de 2008 (2008). http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2008/decreto/d6571.htm

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Thematization of Disability in Children's Literature – Perspectives on the Characters · Renata Junqueira de Souza & Sílvia de Fátima Pilegi Rodrigues

Decreto nº 3.298, de 20 de dezembro de 1999 (1999). http://www.planalto.gov.br/ccivil_03/decreto/d3298. htm

Dowker, A. (2013). A representação da deficiência em livros infantis: Séculos XIX e XX. *Educação & Realidade*, *38*(4), 1053–1068.

Dyches, T. T., & Prater, M. A. (2005). Characterisation of developmental disabilities in children's fiction. *Education and Training in Developmental Disabilities*, *40*(3), 202–216.

Emenda Constitucional nº 65, de 13 de julho de 2010 (2010). http://www.planalto.gov.br/ccivil_03/Constituicao/Emendas/Emc/emc65.htm

Flynn, K. S. (2001). Developing children's oral language skills through dialogic reading: Guidelines for implementation. *Teaching Exceptional Children*, *44*(2), 8–16. https://doi.org/10.1177/004005991104400201

Freire, S. (2008). Um olhar sobre a inclusão. *Revista da Educação*, *16*(1), 5–20. http://hdl.handle.net/10451/5299

Hughes, C. (2012). Seeing blindness in children's picturebooks. *Journal of Literary & Cultural Disability Studies*, *6*(1), 35–51.

Instituto Brasileiro de Geografia e Estatística. (2012). *Censo brasileiro de 2010*. IBGE

Kirchof, E. R., Bonin, I. T., & Silveira, R. M. H. (2013). Apresentação – Literatura infantil e diferenças. *Educação & Realidade*, *38*(4), 1045–1052. https://doi.org/10.1590/S2175-62362013000400002

Lei nº 9.394, de 20 de dezembro de 1996 (1996). http://www.planalto.gov.br/ccivil_03/leis/l9394.htm

Lei nº 13.146, de 6 de julho de 2015 (2015). http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm

Lei nº 13.005, de 25 de junho de 2014 (2014). http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2014/lei/l13005.htm

Machado, M. Z. V. (2014). Gêneros literários para crianças. In I. C. Frade, M. G. C. Val, & M. Bregunci (Eds.), *Glossário Ceale de termos de alfabetização, leitura e escrita para educadores*. CEALE; Faculdade de Educação da UFMG.

Paiva A. (2008). A produção literária para crianças: Onipresença e ausência das temáticas. In A. Paiva, & M. Soares (Eds.), *Literatura infantil: Políticas e concepções* (pp. 35–52). Autêntica.

Pimentel, F. (1952). *Histórias da avozinha*. Livraria Quaresma.

Portaria nº 1.793, de dezembro de 1994 (1994). http://portal.mec.gov.br/seesp/arquivos/pdf/port1793.pdf

Prater, M. A. (1999). Characterisation of mental retardation in children's and adolescent literature. *Education and Training in Mental Retardation and Developmental Disabilities*, *34*(4), 418–431.

Price, C. L., Ostrosky, M. M., & Mouzourou, C. (2016). Exploring representation of characters with disabilities in library books. *Early Childhood Education Journal*, *44*(6), 563–572. https://doi.org/10.1007/s10643-015-0740-3

Quicke, J. B. (1985). *Disability in modern children's fiction*. Croom Helm.

Resolução CNE/CEB nº 2, de 11 de setembro de 2001 (2001). http://portal.mec.gov.br/cne/arquivos/pdf/CEB0201.pdf

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Sipe, L. R. (2012). Revisiting the relationships between text and pictures. *Children's Literature in Education*, *43*, 4–21. https://doi.org/10.1007/s10583-011-9153-0

Sonnenschein, S., & Munsterman, K. (2002). The influence of homebased reading interactions on 5-year-olds' reading motivations and early literacy development. *Early Childhood Research Quarterly*, *17*(3), 318–337. https://doi.org/10.1016/S0885-2006(02)00167-9

Souza, R. J., & Bortolanza, A. M. E. (2012). Leitura e literatura para crianças de 6 meses a 5 anos: livros, poesias e outras ideias. In R. J. Souza, & E. A. Lima (Eds.), *Leitura e cidadania* (pp. 67–90). Mercado de Letras.

Wopperer, E. (2011). Inclusive literature in the library and the classroom: The importance of young adult and children's books that portray characters with disabilities. *Knowledge Quest*, *39*(3), 26–34.

Yenika-Agbaw, V. S. (2011). Reading disability in children's literature: Hans Christian Andersen's tales. *Journal of Literary & Cultural Disability Studies*, *5*(1), 91–107.

Zilberman, R., & Lajolo, M. (1993). *Um Brasil para crianças – Para conhecer a literatura infantil brasileira: História, autores e textos*. Global.

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Professional (Re)Integration of Persons with Disabilities: Perceptions of the Contract Employment Insertion/Contract Employment Insertion+ Measures by Beneficiaries and Promoters

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Abstract

The Portuguese State recognises the right of persons with disabilities to employment on equal terms with non-disabled persons. Nonetheless, many employers still resist the idea of hiring someone with a disability. For this reason, the action of the State is determinant to change attitudes towards disability and promote the hiring of persons with disabilities in the open labour market. These actions are materialised through public policies. This article reports the results of an exploratory and qualitative study on the measures known as contract employment insertion/ contract employment insertion+ (CEI/CEI+), implemented in the region of Lisbon and the Tagus Valley. It examined the perception of three stakeholders — 16 male and female beneficiaries with disabilities, nine institutions promoting these measures, and seven non-profit organisations devoted to training and employment of persons with disabilities — to know their perspectives on the potentialities and limitations of these measures. The results reveal that the CEI/CEI+ measures only provide a temporary remedy to the problem of unemployment among persons with disabilities, which hinders their access to a socioeconomically independent life that is sustainable. Nonetheless, respondents do not deny the importance of these measures, viewing them as an excellent opportunity to showcase their professional skills and reinforce their self-esteem and self-worth. The data obtained in this study are discussed according to various models approaching disability. In the end, we formulate a few recommendations to maximise the effects of these measures.

Keywords

persons with disabilities, public policy, professional (re)integration, CEI/CEI+ measures

(Re)Inserção Profissional de Pessoas com Deficiência: Perceções das Medidas Contrato Emprego Inserção e Contrato Emprego Inserção+ por Beneficiários e Promotores

Resumo

O Estado português reconhece à pessoa com deficiência o direito ao trabalho, de forma igualitária às demais pessoas. No entanto, muitos empregadores resistem ainda à ideia de

contratar uma pessoa com deficiência. Neste sentido, a ação do Estado é determinante para a mudança de atitudes face à deficiência e para promover a contratação de pessoas com deficiência no mercado aberto de trabalho. Estas ações materializam-se através de políticas públicas. Este artigo reporta os resultados de um estudo de natureza exploratória e qualitativa sobre as medidas contrato emprego inserção e contrato emprego inserção+ (CEI/CEI+), realizado na região de Lisboa e Vale do Tejo, que analisou a perceção de três *stakeholders* — 16 beneficiários/as com deficiência, nove entidades promotoras das medidas e sete entidades promotoras de formação e emprego de pessoas com deficiência — com o objetivo de conhecer as suas perspetivas sobre os aspetos facilitadores e as limitações na aplicação destas medidas. Os resultados obtidos revelam que as medidas CEI/CEI+ apenas oferecem uma resposta temporária ao problema do desemprego das pessoas com deficiência, o que dificulta o acesso de forma sustentável a uma vida socioeconomicamente independente. Não obstante, os inquiridos não negam a importância destas medidas, considerando-as uma boa oportunidade para demonstrarem as suas competências profissionais e reforçar a autoestima e valorização pessoal. Os resultados obtidos com este estudo são discutidos à luz dos modelos de abordagem à deficiência e são formuladas algumas recomendações, com vista a potencializar os efeitos destas medidas.

Palavras-chave

pessoas com deficiência, políticas públicas, (re)inserção profissional, medidas CEI/CEI+

Introduction

Access to work is a fundamental right. In theory, everyone is equal before the law. Therefore, everyone should have the right to pursue a professional activity (Convenção dos Direitos das Pessoas com Deficiência, 2006). On the one hand, this contributes to their economic survival and, on the other, to their happiness, fulfilment, and a sense of purpose (Associação Portuguesa de Deficientes, 2012; Simonelli & Camarotto, 2011; Vieira et al., 2015).

Nonetheless, persons with disabilities are still viewed as dependent, incapable, and ill (Vieira et al., 2015). In fact, they constitute one of the most disadvantaged groups in our society, both socially and economically. The prevailing negative view of persons with disabilities, which characterises the so-called "medical and individual model", also extends to the world of labour.

Therefore, despite the guarantee and recognition of these rights, the fact remains that many persons with disabilities still face more significant difficulties when looking for work, not due to their physical or intellectual abilities, but due to the intersection of numerous social factors that restrict their employability, namely: discrimination and lack of disability awareness by employers; lack of accessibility in the workplace; employers' ignorance regarding disability, including the specific needs and the particular skills of persons with disabilities; lack of effective incentive and support; failure to ensure that persons with disabilities effectively enjoy good quality education and training, resulting in a mismatch between their abilities and the needs of the labour market (Associação Portuguesa de Deficientes, 2012; Vieira et al., 2015).

Similarly to other public initiatives, the contract employment insertion/contract employment insertion+ (CEI/CEI+) measures were created to address some of these challenges, but, as far as we know, they have not been assessed yet to determine their adequacy and efficacy. This exploratory study strives to understand how the CEI/CEI+ measures are viewed by recipients with disabilities and promoting organisations. This study aims to assess how effective the measures mentioned above are, based on the perspective of their recipients and the organisations that promote them on the ground, contributing to research on public policy and the professional (re)integration of persons with disabilities. From the data that we have gathered and analysed, we also reflect on how the implementation of these measures contributes to the perpetuation of individualised and stigmatising views of disability, or breaks with such views, highlighting that the State and society are responsible for creating conditions that allow the full participation of persons with disabilities in every realm of social life, including work and employment.

Before that, however, to provide a framework for our analyses, we will start by presenting a summary of different disability models and Portuguese public policy measures trying to promote work among persons with disabilities.

Theoretical Framework: From the Conceptualisation of Disability to Public Policy Regarding Professional Inclusion

Disability exists among all social classes and across the world. Nonetheless, the theoretical discussion on this subject is relatively recent and complex, besides being marked by various conceptual approaches (Organização das Nações Unidas, 1995; Pinto, 2012).

Restricting ourselves to the recent past — from the 20th century onwards — we should highlight the importance of the medical or individual model of disability, which mainly focuses on the insufficiencies and limitations of bodies with impairment, emphasising that they are incapable or abnormal (Fontes, 2009; Martins et al., 2012; Pinto, 2015). This model promotes an understanding of disability and reduces it to a problem that is intrinsic to the individual. Persons with disabilities are seen as different and inferior in aptitudes and skills. In turn, these characteristics are blamed for the difficulties that persons with disabilities face when it comes to full participation in society, at the same time as it absolves society from creating barriers that exclude persons whose bodies depart from the norm.

However, from the 1970s onwards, there was an intense questioning of this perspective, initially led in the United Kingdom by the Union of Physically Impaired Against Segregation. This group denounced the limitations of the medical model, developing a new understanding of disability, which has become known as the "social model of disability". This new conception shifted the focus from the individual to society (Pinto, 2015), distinguishing between disability and impairment. The former refers to the social construct that excludes persons with disabilities, while the latter pertains to the individual's biological characteristics (Fontes, 2009).

The emergence of the social model affected the lives of persons with disabilities in two ways. First, it allowed the identification of political strategies aimed at reducing barriers. If we consider that persons with disabilities are seen as different by the rest of society and kept from participating in it on equal terms, then eliminating these barriers should arise as a priority. The second aspect focused on the individuals with disabilities by replacing a medical view with a social one. In turn, this allowed persons with disabilities to think critically and to mobilise and organise themselves for the first time, demanding to be treated as full citizens, on a par with others (Shakespeare & Watson, 2002). The social model gave rise to a new consciousness regarding the rights of persons with disabilities and the demand for public measures that enact these rights through social inclusion, extensive public policy, and the elimination of barriers (Fontes, 2009; Sousa, 2007). Nonetheless, some have argued that the social model, focusing on the social factors behind exclusion, has neglected the impact of impairment on the lives of persons with disabilities.

Therefore, more recently, the relational or biopsychosocial model has gained traction, "considering the interaction between biology and social context" (Pinto, 2015, p. 187). For example, the United Nations (UN) considers persons with disabilities those who have long-term physical, mental, intellectual or sensory impairments which, interacting with various barriers, may hinder their full and effective participation in society on an equal basis with others (Convenção dos Direitos das Pessoas com Deficiência, 2006). This understanding also prevailed in the Convention on the Rights of Persons with Disabilities (Convenção dos Direitos das Pessoas com Deficiência, 2006), adopted in 2006 by the UN general assembly. Today, this document constitutes an international reference for developing and implementing public policy in this area.

In Portugal, the biopsychosocial perspective is also present in current legislation. For example, Art. 4 of the Decree-Law no. 290/2009 (Decreto-Lei n.º 290/2009, 2009) of October 12, within a professional context, defines the employee with a disability as:

> a person who presents significant limitations to their level of activity and participation, in one or several life domains, deriving from functional and structural changes of a permanent nature, whose interaction with the environment leads to continuous difficulties, namely in securing or maintaining a job or progressing in a career.

According to international law — for instance, the Convention on the Rights of Persons with Disabilities (Convenção dos Direitos das Pessoas com Deficiência, 2006) and other instruments produced by the International Labour Organisation —, workers with disabilities should benefit from special rights, such as adequate rehabilitation, useful employment, and wages equal to other workers without disability (Sequeira et al., 2006). Nonetheless, according to Fontes (2009), the ideology of the medical model still

prevails in the realm of employment, where public policy mainly focuses on the supply side, not that of demand. As an example, note the substantial investment in the creation and implementation of subsidies for the integration of persons with disabilities into the job market, while it would make more sense to create workplaces that are accessible to every person, whether they have a disability or not. On the other hand, employers show discriminatory attitudes linked to their fears about a reality unknown to them. On this point, we should highlight the stereotypes about disability that associate it with diminished productivity, the fear that workers with disabilities may be more prone to injury, or may miss working more often due to health problems caused by their disability, or even the fear of backlash by clients or co-workers (Andrade et al., 2017; Fernandes, 2007). Other authors (Andrade et al., 2017) mention the lack of education pervasive among persons with disabilities, prejudice, and a lack of information as factors that make it harder for this population to enter the job market (Andrade et al., 2017).

The CEI/CEI+ measures aim to respond to some of these challenges within a vast public effort to promote training and employment of persons with disabilities in Portugal. Introduced in 2009, during the 17th Constitutional Governmental, they were created to improve employment levels and encourage long-term unemployed persons' (re)integration into the labour market, including persons with disabilities, enacted by Decree no. 128/2009 (Portaria n.º 128/2009), of January 30, the CEI/CEI+ measures are similar, but they differ in certain aspects. The CEI focuses on unemployed persons (with or without disabilities) enrolled in employment services and receiving unemployment benefits. On the other hand, the CEI+ focuses on unemployed persons (with or without disabilities) enrolled in employment services and recipients of the social reintegration income. The CEI/CEI+ share the same guidelines, and they mainly strive to:

- prevent and fight unemployment;

- promote and support job creation;

- encourage the professional integration of persons with more significant difficulties in entering the job market;

- improve job quality;

- foster local employment in economically disadvantaged areas, thus reducing regional disparities (Portaria n.º 34/2017, 2017).

These measures enable the long-term unemployed to perform socially valuable activities — the so-called "socially necessary work" — which consists of temporary activities/roles/tasks in public or private non-profit organisations (Portaria n.º 128/2009, 2009). We should note that these are not employment measures. Their main goal is to keep the long-term unemployed linked to the job market somehow. Therefore, they should be viewed to keep persons active, not as a substitute for work.

Methodology

The exploratory research on which this article is founded was conducted as a final requirement for a master's degree in public management and policy, completed at the Institute of Social and Political Sciences of the University of Lisbon. The study involved semi-structured interviews with 16 beneficiaries of the CEI/CEI+: 10 men and six women. We have also interviewed seven officers from institutions devoted to training and finding employment for persons with disabilities and nine officers from institutions that promote CEI/CEI+ measures (two central public service institutions, two local public service institutions, and five private institutions of social solidarity). The interviews took place between June 4 and December 28 2018.

We have conducted this interview-based inquiry in Lisbon and the Tagus Valley region since it was the most convenient option. The selection of the institutions devoted to training and finding employment for persons with disabilities was also a choice of convenience.

The contacts of the beneficiaries with disabilities participating in the study were provided by the institutions promoting these measures, where the subjects performed duties. Table 1 summarises the sociodemographic characteristics of our sample.

Sex	Age	Education level	Job title/role
M	28	12th grade	Graphic design
M	27	12th grade	Administrative assistant
F	31	9th grade	Kitchen/cleaning
F	26	12th grade	IT department
M	28	9th grade	Telephone operator
F	47	Bachelor's degree	Newsletter team
M	31	6th grade	Administrative assistant
M	22	9th grade	Administrative assistant
M	33	12th grade	Telephone operator
F	25	12th grade	Administrative assistant
M	32	9th grade	Telephone operator
F	48	12th grade	Telephone operator
F	35	12th grade	Telephone operator
M	40	9th grade	Telephone operator
M	41	Bachelor's degree	Telephone operator
M	50	9th grade	Telephone operator

Table 1 *Sociodemographic characteristics of the studied beneficiaries*

The group is primarily male, their mean age is 34 years old, and most have completed either 9th grade or 12th grade.

For data analysis purposes, a code was assigned to each group of stakeholders, namely: BD — for beneficiaries with disabilities; EP — for the entities hosting beneficiaries; OSL — for the non-profit organisations that train and find employment for persons with disabilities. A number was also assigned to each interviewee, corresponding to the order of the interview within the selected group.

Results

Our analysis focused on the experiences of the beneficiaries, employers, and institutions that train or find employment for persons with disabilities concerning the CEI/CEI+ measures. We have tried to identify what they considered to be the positive aspects and limitations of these measures and suggest possible ways of improving them. Below, we highlight some of the results gathered in the interviews.

Positive Aspects of the Contract Employment Insertion/Contract Employment Insertion+

The three interviewed groups mentioned several positive aspects. The first pertains to the acknowledgement that the CEI/CEI+ measures help unemployed persons, emerging as an opportunity for the beneficiaries to demonstrate their professional abilities and skills. The three groups agree that participation in these programmes allows the beneficiaries to contact the world of work, thus creating or maintaining work habits and giving them a reason to leave the house. Moreover, they fight social exclusion and unemployment, increase the recipients' self-esteem and responsibility, and acquire new experiences. Therefore, these measures constitute an opportunity to enter or re-enter the job market and to retrain or relearn: "a good thing about them is that they get you out of the house, we gain autonomy and have contact with the world of work, which then starts getting to know us, those are the most significant advantages" (BD16).

> I think these measures are essential. As a public institution, we should welcome these measures (...) as a way to motivate them and allow them to have contact with the world of work, so they can acquire new experiences and see different realities (...) these projects might give them the opportunity to enter the job market because many have never worked. They do not have work habits, routines, or schedules, which will help them create these routines and follow them so they can have contact with the world of work. (PI2)

> There is the question of training and retraining. Thanks to this measure, a person who had a particular profession a long time ago can now update

their skills. I think that is the good thing about it. It allows a person to regain

work skills. (NPO3)

Moreover, according to the three groups' perceptions, the CEI/CEI+ measures are considered a springboard for the future professional integration of persons with disabilities, at least in some cases. That is the greatest hope of the beneficiaries, who expect to secure a permanent job and achieve an independent life — a desire shared by all adults.

If we restrict ourselves to the promoting institutions and those that train and find employment, these measures also represent direct financial advantages for the former since they secure human resources. Even though these workers remain with the organisations for a limited amount of time, it is a way to reduce expenses with staff. In addition to this financial aspect, another noted advantage is that the institutions have up to 12 months to assess if the beneficiaries are good at performing a particular task, turning these measures into a valuable tool to filter and find competent workers at a reduced cost. "The advantages are entirely financial, besides the fact that we can discover valuable persons through these measures without that representing a high cost for the organisation" (PI3).

> The CEI gives us the time to assess a person's professional abilities. Today, public procurement does not give us enough time, so, for me, the CEI are crucial because they allow me to assess a person indeed. It's extremely helpful to be able to say, "OK, this person has good skills, they will be a good worker", or not. So, if there's the chance, the person with a CEI contract can be more easily recruited. (OSL7)

Finally, the institutions promoting the training and employment of persons with disabilities believe that the CEI/CEI+ measures allow the trainees to practice what they learned during training and earn an income simultaneously.

Limitations of the Contract Employment Insertion/Contract Employment Insertion+

Despite recognising these advantages, the beneficiaries, promoting institutions and vocational training institutions have also pointed out many limitations. The first is that the workers' monthly income is below the national minimum wage. That was the negative aspect most often mentioned by the three interviewed groups, who consider this income insufficient to face living expenses: "in terms of standard of living, this is not enough for us to live on because we want to build a life, have a house, be independent, and with this bit of money, we can't" (BD14).

> I have a basic contract + lunch subsidy + transport subsidy... all of that to-
> gether is less than the minimum wage, and I feel that isn't fair... I'm happy
> to be working here, of course, but I'd like to earn a bit more. (BD2)

Even though the goal of the CEI/CEI+ measures is not to replace a job, in many cases, that is what happens exactly. Many promoting institutions, especially the public sector, resort to these measures because they need human resources but cannot hire externally. That leads many promoters to undertake successive renovations of the measures CEI/CEI+ to address human resources needs which are permanent rather than temporary as the measures suggest: "the problem with public administration is that we can only hire internally or through external recruitment. external hires take ages, and there have to be authorisations and whatnot" (PI7).

> There was always this juggling of deadlines, in the sense that when one was
> over, we applied for another, and when that was finished, we started apply-
> ing for a new one. That was the only way to guarantee minimum services.
> (...) This measure isn't well-thought-out. It's a quick fix. For one year, we
> have this solution, and then we'll see when there's another CEI+. This can
> go on for one year, two years, three years, four years. (BD7)

One of the promoting institutions (PI7) reported they tried to hire a beneficiary after the CEI+ measure was over. Nonetheless, since the program only covers socially useful work, the institution found it hard to argue that the job performed by the beneficiary was vital:

> it was a problem for us. How are we going to prove that what he's doing is
> 'socially useful'? He's needed in the organisation, and that's what we went
> with; we said he was an asset and had already shown various skills. We
> said that he would be integrated into the [name of the department], provid-
> ing face-to-face assistance, writing to persons with disabilities, families, or-
> ganisations, etc., but it wasn't easy because of the socially helpful activities
> mentioned in the CEI+. (EP7)

Therefore, expectations are generated that rarely materialise: for the beneficiaries, who view the participation in a CEI/CEI+ programme as work and hope to see their CEI/CEI+ be transformed into a long-term work contract, which rarely happens; and for the promoting institutions that manage to address permanent staffing needs during 12 months, but at the end of this period see these workers leave and have to once more deal with unmet human resources needs.

Another limitation often mentioned by the promoting institutions and those devoted to vocational training is the excessive bureaucracy when applying for and implementing

these measures. That is considered one of the main obstacles to their success: "often, we don't resort to the CEI because it involves a lot of bureaucracy, and it takes a long time before a decision is made" (NPO7).

> The IEFP [Institute for Employment and Vocational Training] provides funding, but we have to do the research ourselves. However, they could make the process easier and create a kind of manual of procedures that would be sent to all institutions (…) the information we find online is certainly our greatest help at the moment, but there's so much information (…) and so detailed (…) see, sometimes we read all of the information, and it seems that point 2 cancels point 3, point 3 cancels point 1 (…) it's a bit complicated, that's what I'm trying to say. (NPO4)

The beneficiaries complain about fruitless attempts to obtain clarification, the excess of procedures, and contradictory information conveyed by different IEFP employees, as we can observe in the following testimonies:

> I contacted them once to find out how many CEI+ were allowed in a single institution, and they gave me such a ridiculous answer that I haven't called them again. Their answer was: "It depends on who is analysing". And I said: "But there's a law. What does the law say?" to which they answered: "Right, but it's very vague; it depends on who is analysing". I don't know if the person on the phone simply didn't know, or if they didn't want to give me that information, but when I needed it and didn't get it, my doubt was not solved. (BD7)

> I sent a few emails but didn't receive any timely replies. So all I could do, when the time came, was to say to someone in charge: "Here are the emails I sent, the calls I made, and these are the answers I obtained, so if we want to try this type of project again we need more time to plan things and greater persistence". (BD10)

> I've tried to contact them, and the experience was traumatising… the treatment I received was deplorable and plain awful. At a certain point, they told me: "Sorry, but what are you doing here? I've nothing for you; go home". And I replied: "Forget it, I'll look for something myself since I can't count on you". I think I only contacted the jobcentre twice, and both times were discouraging, even humiliating. (BD15)

In addition to bureaucracy, there are gaps in the IEFP services related to their online platforms, support lines and email, making it hard to obtain answers on time.

Furthermore, the beneficiaries recurrently mentioned a lack of inspection by the IEFP, which is another disadvantage since many institutions do not abide by the legislation regulating these measures, especially concerning the execution of "socially useful work" the non-occupation of a job position.

Even though the contract stipulates that the CEI/CEI+ measures do not employ the beneficiaries, only nine were actively looking for work from the 16 persons we have interviewed, which they primarily did online. Despite the majority worrying about not having a stable/permanent job, others have mentioned that they chose not to look for work. Five subjects said that they weren't looking for a job because: (a) they feel content in the organisation where they perform their role/task and don't see the need to look for a job; (b) they believe that the job market is not prepared to integrate persons with disabilities; and (c) they hope to join the program for the extraordinary regularisation of precarious employment contracts of the public administration (Prevpap).

Generally speaking, even though the CEI/CEI+ are not exclusively directed at persons with disabilities, they are seen as tools that allow youngsters with disabilities to transition into adult life, an alternative to being admitted into an occupational activities centre (CAO). Therefore, they act as a road map for the social and professional (re)integration of persons with disabilities. Because youngsters/adults with disabilities represent the possibility of an independent socioeconomic life, which everyone (with or without disabilities) expects, finally, it comes with significant financial advantages for the institutions promoting these measures.

Recommendations

We have also gathered recommendations for improving the CEI/CEI+ measures, with the view to making them more efficient. The first recommendation put forth by most of the persons interviewed in the three groups pertains to more promptness and a more efficient and rigorous inspection by the IEFP. Moreover, they suggest that the procedures be revised, making them less bureaucratic and lengthy, which is one of the main obstacles to joining the CEI/CEI+ program. Besides the need to simplify, they also suggest that the IEFP delegate part of its powers to the resources centres, allowing the latter to assess candidates' profiles more thoroughly to properly match their skills and limitations to the roles that they perform:

> I think persons should be more closely supported since they aren't used to
> routines, struggle with schedules, and have never worked before in many
> cases. I've noticed that they sometimes find it hard to conform to the pro-
> ject's rules, namely regarding attendance. (PI2)

> IEFP has few resources in many of its structures, and sometimes the structure itself rests too heavily on bureaucracy. As a consequence, these youngsters are somewhat abandoned. It requires an institution willing to deal with the matter and spend months chasing papers, and sometimes their certificates have errors, and you need to talk to the institution. So, this backstage work needs to be done and that sometimes they can't do it themselves. If no one does it, the process dies. (PI6)

Another recommendation has to do with the continuity of the measures after the end of the contract when the worker is competent, and the organisation is willing to keep them. That would turn the experience into a permanent contract that the State financially supports so that the beneficiaries can become permanent workers and tax-payers, similar to workers without disabilities:

> it would be helpful if the organisation had an automatic integration scheme to become permanent employees. I think that would be the most useful measure since we are talking about public institutions that actually need persons, and there are certain tasks where persons can really be put to good use. (BD15)

Moreover, it was generally recommended to reinforce the practices used by the IEFP to raise awareness, inform, dispel doubts and myths, and intensively fight ignorance around the issue of disability. It was also stressed by many that there should be more effective public policy centred on intervening in schools as a way to demystify and fight against the stereotypes that still prevail about disability:

> there's no doubt that education is crucial... a few years ago, we did a study on the profile of employers who hired persons with disabilities, and we concluded that most had known persons with disabilities, at a professional or personal level. If we had a truly inclusive society, where everyone had a voice, if children were familiarised with diversity and inclusion from early on when they become entrepreneurs and joined the work world themselves, things would be completely different. So, it would have a positive effect in terms of demystifying prejudice and stereotypes. We must certainly start from there. (NPO6)

Conclusions and Discussion

The article presents the actual results of an exploratory scientific study. The data we have gathered suggests that the CEI/CEI+ measures are a short-term solution and that they generally fail to offer sustained access to the job market after the temporary

measures have ended. Nevertheless, by joining these programmes, the beneficiaries create the expectation of securing a long-term job, developing a relationship with the institution and co-workers, and hoping to remain as employees after the CEI/CEI+ contract has ended. Upon seeing their expectations unfulfilled, many interviewees realise that these contracts do not serve as springboards into the job market. With the meagre income during the programme, accessing an independent socioeconomic life becomes an almost impossible dream.

Moreover, one of the main problems mentioned is using the CEI/CEI+ measures to meet permanent staffing needs. That goes against the legislation that regulates the CEI/CEI+, according to which the focus should be on "socially useful work". Nonetheless, many social institutions adhering to the CEI/CEI+ programme are financially fragile, which keeps them from hiring permanently. As for the institutions of the central/local administration, they believe that the hiring process following the end of the CEI/CEI+ is too bureaucratic and complex — they must request a permit before they can open a public recruitment process, which is lengthy and cumbersome (i.e., rendering this possibility impractical). Therefore, in both cases, the CEI/CEI+ measures have practically no effect on creating long-term jobs. In fact, in 2014, a union leader defended in a press conference that the CEI/CEI+ "are nothing but a way of 'removing a few unemployed from unemployment statistic'" ("'*É Urgente Pôr Fim à Exploração dos Desempregados*', afirma CGTP", 2014, para. 2).

In summary, to answer the primary question posed in this research — *how are the CEI/CEI+ viewed by the beneficiaries with disabilities and promoting institutions? —*, our data suggest that, even though these measures do not produce the expected results, the three groups we have interviewed recognise their importance. It constitutes an excellent opportunity for the beneficiaries to showcase their professional skills, allowing them to create/maintain work habits. Moreover, they provide professional and personal fulfilment. The institutions that adhere to the CEI/CEI+ measures highlight the financial benefits associated with them and the opportunity to assess the professional skills of the workers. In other words, they believe that these programmes constitute powerful tools for finding good workers at a reduced rate. Finally, the organisations that promote the vocational training and employment of persons with disabilities see them as an opportunity for trainees to practice the skills they acquired during training and receive an income in the process.

Reflecting now on these results from the perspective of the disability models we mentioned earlier, we must conclude that the CEI/CEI+ measures are insufficient to remove barriers and rectify the exclusion to which persons with disabilities are subjected in the job market. They might even have perverse effects. As we have seen in the analysed sample, these programmes favour the use of low-cost labour. Consequently, they cannot guarantee true financial independence for those who benefit from them. Moreover, they

do not directly contribute to creating long-term jobs, despite frequently solving the permanent staffing needs of the promoting institutions. These measures are presented to improve the employability of workers in a particular unemployment situation and stimulate their (re)integration into the labour market. However, they can reinforce the social perception that the failure to secure a stable job is due to their impairment (cf. medical or individual model), and not to the structural obstacles these persons face when they try to get a job (which reflects the biopsychosocial model).

The conclusions presented here are based on the data we have gathered, but they are not a point of arrival — they should serve as the starting point of a more extended and more complex discussion. Even though many governments are increasingly concerned with the vocational training and employment of persons with disabilities, the materialisation of these goals has undoubtedly been slow.

However, "not to throw the baby out with the bathwater" is crucial. Despite the fragilities that we have found, which should be corrected, there are positive aspects to these measures that should be expanded and reinforced. Therefore, we believe it is necessary to pursue a scientific and political reflection around this subject, taking into consideration the recommendations of the interviewees, namely: greater agility and less bureaucracy in the IEFP processes; consideration of alternatives to long-term hiring after 12 months (maximum duration of the CEI/CEI+); creation of an efficient inspection team by the IEFP, which should devote itself to the employability of persons with disabilities; raising the monthly income to the same level as the Portuguese minimum wage; elimination of the "socially useful work" category; delegation of powers from the IEFP to the inclusion resource centre, which should manage these processes; the IEFP should work on raising awareness and demystifying disability among public and private organisations, to fight obstacles that keep persons with disabilities from being hired.

In a follow-up to this investigation, we also recommend developing further research to ascertain the number of persons with disabilities who enter the job market (by signing a long-term work contract) after completing the CEI/CEI+ period.

Translation: Ana Macedo

References

Andrade, A., Silva, I., & Veloso, A. (2017). Integração profissional de pessoas com deficiência visual: Das práticas organizacionais às atitudes individuais. *Revista Psicologia: Organizações e Trabalho*, *17*(2), 80–88. https://doi.org/10.17652/rpot/2017.2.12687

Associação Portuguesa de Deficientes. (2012). *O emprego e as pessoas com deficiência.* Instituto Nacional para a Reabilitação.

Convenção dos Direitos das Pessoas com Deficiência, December 13, 2006, https://www.inr.pt/resultados-de-pesquisa/-/journal_content/56/11309/44797?p_p_auth=jZgndlTI

Decreto-Lei n.º 290/2009. Diário da República n.º 197/2009 — I Série (2009). https://data.dre.pt/eli/dec-lei/290/2009/p/cons/20150617/pt/html

"'É urgente pôr fim à exploração dos desempregados', afirma CGTP". (2014, December 1). Esquerda. https://www.esquerda.net/artigo/e-urgente-por-fim-exploracao-dos-desempregados-afirma-cgtp/35005

Fernandes, C. (2007). Empregabilidade e diversidade no mercado de trabalho — A inserção profissional de pessoas com deficiência. *Cadernos Sociedade e Trabalho* (8), 101–113.

Fontes, F. (2009). Pessoas com deficiência e políticas sociais em Portugal: Da caridade à cidadania social. *Revista Crítica de Ciências Sociais, 86*, 73–93. https://doi.org/10.4000/rccs.233

Martins, B., Fontes, F., Hespanha, P., & Berg, A. (2012). A emancipação dos estudos da deficiência. *Revista Crítica de Ciências Sociais, 98*, 45–64.

Organização das Nações Unidas. (1995). *Normas sobre a igualdade de oportunidades para pessoas com deficiência.* Secretariado Nacional para a Reabilitação e Integração das Pessoas com Deficiência.

Pinto, P. (2012). *Dilemas da diversidade: Interrogar a deficiência, o género e o papel das políticas públicas em portugal.* Fundação Calouste Gulbenkian; Fundação para a Ciência e a Tecnologia.

Pinto, P. (2015). Modelos de abordagem à deficiência: Que implicações para as políticas públicas? *Ciências e Políticas Públicas, 1*(1), 174–200.

Portaria n.º 128/2009, Diário da República n.º 21/2009, Série I de 2009-01-30 (2009). https://data.dre.pt/eli/port/128/2009/1/30/p/dre/pt/html

Portaria n.º 34/2017, Diário da República n.º 13/2017, Série I de 2017-01-18 (2017). https://data.dre.pt/eli/port/34/2017/p/cons/20200827/pt/html

Sequeira, A., Maroco, J., & Rodrigues, C. (2006). Emprego e inserção social das pessoas com deficiência na sociedade do conhecimento: Contributo ao estudo da inserção social das pessoas com deficiência em Portugal. *Revista Europeia de Inserção Social, 1*(1), 3–28. http://hdl.handle.net/10400.12/1856

Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, *2*, 9–28. https://doi.org/10.1016/S1479-3547(01)80018-X

Simonelli, A., & Camarotto, J. (2011). Activity analysis for inclusion of disability people at work: A proposition model. *Gestão & Produção, 18(1)*, 13–26. https://doi.org/10.1590/S0104-530X2011000100002

Sousa, J. (2007). Deficiência, cidadania e qualidade social: Por uma política de inclusão das pessoas com deficiências e incapacidades. *Cadernos Sociedade e Trabalho*, (8), 38–56.

Vieira, C., Vieira, P., & Francischetti, I. (2015). Professionalization of disabled people: Reflections and possible contributions from psychology. *Revista Psicologia: Organizações e Trabalho, 15(4)*, 352–361. https://doi.org/10.17652/rpot/2015.4.612

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Workers With Down Syndrome: Autonomy and Wellness at Work

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Abstract

This article presents a research report that was replicated in the city of São Paulo (Brazil) of the one developed in Portugal by Veiga and Fernandes (2014). It reflects on some research data, which demonstrate the role, importance and impact of being admitted in the world of work in the lives of workers with Down syndrome, including the feeling of wellness, autonomy, and friendship acquired. These workers were interviewed, as were their immediate bosses, friends and co-workers, and the observations made at the workplace. Knowing that social inclusion does not occur outside work, we highlight the importance of public policies in promoting rights and defending the rights already achieved, including the active participation of people with Down syndrome in society. This study showed that the achievement of a job made it possible to increase self-esteem, to develop autonomy and wellness of workers, providing them with achievements in the affective-social field (dating and friendships), in the family, economic and professional spheres, albeit with restrictions. The job also provided the feeling of being more useful and accepted by peers ("a sense of belonging"). It also allowed the possibility of contributing to the family and making plans for the future, with the same projects as any young adult, such as travelling, getting married and having children.

Keywords

autonomy, wellness, intellectual disability, labor market, inclusion

Trabalhadores com Síndrome de Down: Autonomia e Bem-Estar no Trabalho

Resumo

Este artigo apresenta o relato de uma pesquisa que foi uma reaplicação na cidade de São Paulo (Brasil) da desenvolvida em Portugal por Veiga e Fernandes (2014). Reflete sobre alguns dados obtidos, os quais demonstram o papel, a importância e o impacto do ingresso no mundo do trabalho na vida de trabalhadores com síndrome de Down, incluindo o sentimento de bem-estar, de autonomia e as relações de amizade adquiridas. Foram entrevistados não apenas

esses trabalhadores, mas também seus chefes imediatos, amigos e colegas de trabalho, e foram realizadas também observações nos locais de trabalho. Sabendo que a inclusão social não se concretiza de modo alheio ao mundo do trabalho, destacamos a importância das políticas públicas, quer na promoção de direitos, quer na defesa dos direitos já conquistados, inclusive o da participação de pessoas com síndrome de Down na sociedade. O resultado deste estudo evidenciou que a conquista do emprego possibilitou o aumento da autoestima, o desenvolvimento da autonomia e do bem-estar dos trabalhadores, proporcionando-lhes conquistas no campo afetivo-social (namoros e amizades), nos âmbitos familiar, econômico e profissional, ainda que com restrições. Além disso, o emprego propiciou a percepção de se sentirem mais úteis e aceitos pelos pares ("sensação de pertencimento"), bem como a possibilidade de poderem contribuir para a família e de traçarem planos para o futuro, com projetos semelhantes aos de qualquer jovem adulto, como viajar, casar e ter filhos.

Introduction

Firstly, it is worth noting that the data and the analysis presented in this article stem from the chapter "Autonomia e Bem-Estar Após o Ingresso no Mundo do Trabalho" (Autonomy and Well-Being After Entering the World of Work), from the book *InclusãoProfissional e Interação Social de Pessoas com Deficiência Intelectual* (Professional Inclusion and Social Interaction of People with Intellectual Disabilities; Crochick, 2019), which reports the research conducted between 2017 and 2018 in the city of São Paulo involving workers with Down syndrome. The respective research was guided and coordinated by José Leon Crochick, with the participation of the members of the Laboratório de Estudos sobre o Preconceito of the Institute of Psychology of the University of São Paulo, and funded by the Fundação de Amparo à Pesquisa do Estado de São Paulo (Crochick, 2019).

According to Pereira-Silva et al. (2018), the inclusion of workers with disabilities in the labour market is a guaranteed constitutional right; however, the reality in Brazil is different when we verify the quality and working conditions that companies offer to these people, in addition to the high number of such workers who are still unemployed in the country. Even as corporate practices related to social responsibility increase, the adaptation of corporate environments to welcome and respect diversity needs to be significantly improved. Still, for Pereira-Silva et al. (2018), the inclusion of workers with intellectual disabilities in the labour market has been more satisfactory than unsatisfactory.

In this article, we organise the research results with regard to the consequences in the lives of the participating subjects of being admitted into the labour market, based on interviews and observations. Thus, we surveyed whether employment affected their lives, including their circle of friends, whether it brought about changes in existing friendships and whether it favoured new relationships. Regarding autonomy, we analysed whether participants began to organise, plan and manage their lives more actively after being

employed and whether admission into the labour market led to changes in workers' wellness, that is if after being employed, they began to feel and consider themselves happier and/or more satisfied people.

Justification

According to Leite and Lorentz (2011), the amount of research reported is small regarding workers with Down syndrome, which alone justifies this study.

Although we acknowledge this work bears the contradictions of the current capitalist society, subject to a series of questions, including humanitarian ones, it is undeniable that it is also one of the means that enable greater social inclusion and the possibility of having a more dignified life. Leite and Lorentz (2011) and Pereira-Silva et al. (2018) also point it out and highlight greater autonomy and new possibilities for activities. Work can provide the satisfaction of being recognised as important workers — with or without disabilities — by the people who matter to them.

Work, however, can also be a source of suffering due to frustrations that it can create, such as colleagues hostility; dissatisfaction with working conditions and/or wages; sacrificing the time one could dedicate to more pleasurable activities or even the non-recognition of one's ability at work. Regarding the person with a disability, marginalisation or segregation may also happen at the workplace, as in school life (Crochick et al., 2013; Leite & Lorentz, 2011). On the other hand, the research carried out by Leite and Lorenz (2011) and Pereira-Silva et al. (2018) found, as will be seen later, a high degree of satisfaction for workers, their peers and families, by providing more autonomy and more personal wellness, as well as the development of skills essential for all aspects of life, such as time management — and, last but not least, in some cases, new friendships.

The research by Alves et al. (2019) in the chapter "Autonomia e Bem-Estar Após o Ingresso no Mundo do Trabalho" (Autonomy and Well-Being After Entering the World of Work) also found that, for people with Down syndrome, these advantages and frustrations also occur and can be alleviated, according to education, family support and, above all, the support of employers and colleagues. The research conducted by Pereira-Silva & Furtado (2012) also indicates the same trends for workers with intellectual disabilities in general: work improves the worker's quality of life, depending on how much support there is from all. They also add that this improvement depends on individual abilities and obstacles to face and emphasises the importance of companies' necessary support. These authors verified the importance that these workers attach to the activities arising from their jobs, as these provide greater satisfaction and personal autonomy. They also cite studies showing that the need to associate methods with the fulfilment of goals strengthens the possibility of thinking about life projects.

The laws that favour the employability of workers with disabilities are essential. However, Pires et al. (2007), and Leite and Lorentz (2018), argue that they are not enough,

as there is a need for the recognition of these workers' capabilities and to provide them, where appropriate, with access to vocational courses and financial support either from companies or the government.

The research by Veiga and Fernandes (2014), which we replicated in Brazil and resulted in the above-cited book, made many significant contributions to this area. Among them is the need to raise awareness of the appropriate behaviours for social coexistence and the help of teams specialised in mediating between workers with intellectual disabilities and their colleagues and bosses, since school education does not always prepare them for that.

The research' objective is to verify whether the admission of young people with Down syndrome in the labour market led to a more satisfactory social life, increased autonomy regarding different activities and the opportunity to develop projects for their lives.

Method

Participants

The research that originated the data presented in this article, which was a replication with adaptations of the research conducted in Portugal by Veiga and Fernandes (2014), adopted the following method: it selected as participants 20 young people with Down syndrome who had been working in the same job for at least 1 year; one of them lost his job in the course of data collection. These participants were also joined in the study by one work colleague and one friend they appointed, their immediate bosses, family members and an educational counsellor or similar from the school institution where each participant graduated.

These workers ranged from 21 to 37 years old, of both sexes, and approximately half were trained in special institutions and the rest in regular schools and classrooms. In addition, 17 of these participants lived in neighbourhoods with a high human development index (HDI), and three in neighbourhoods with a medium HDI. These participants will be assigned the letter "P" plus a number to facilitate the exhibition.

Material

Interview scripts were used in the research developed by Veiga and Fernandes (2014), with some adaptations in vocabulary and format. The scripts for workers with Down syndrome were divided into six parts: (a) general characteristics; (b) social relationships and interactions; (c) psychological wellness and personal satisfaction; (d) employment; (e) personal skills; (f) integration into the community. The script of interviews with friends had questions about the importance of work and how it contributed to the autonomy and wellness of the friend with Down syndrome; the scripts addressed

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to colleagues and bosses were intended to check satisfaction of the worker with Down syndrome with work, autonomy, and self-satisfaction. The family members were asked, through script interviews, about the importance of the job for the family and worker and how work contributed to their relative's autonomy and happiness. The researchers also observed these workers in their workplace to obtain data on their autonomy, performance and satisfaction at work.

Procedure

Data Collection

The workers with Down syndrome were indicated by Instituto Jô Clemente and Instituto Simbora Gente, both of which offer different kinds of activities for people with intellectual disabilities. The participants and family members were invited to participate in the survey by telephone; participants indicated friends to be interviewed, and permission was requested to interview colleagues and bosses at the workplace, where observations were also made. The interviews with workers with Down syndrome lasted around 1 hour and a half, and the other interviews generally lasted 45 minutes. The data were collected in person at the workplace and the relatives' homes between 2017 and 2018.

Data Analysis

Quantifiable data were analysed using descriptive statistics such as frequency, mean and standard deviation, and Spearman correlation coefficients. For the qualitative analysis of the answers to the other questions, we used data from the different interviews to be contrasted and supplemented to achieve greater accuracy of what was researched and broaden the discussion. The primary reference used was the critical theory of society. We also used the HDI of the area where the participants with Down syndrome lived to infer their socioeconomic level.

Results

We now present some quantitative and qualitative data regarding the research conducted with workers with Down syndrome to understand if the insertion of these people in the labour market helped expand their circle of friends, their autonomy, wellness and life projects.

Circle of Friendships

Of the 20 participants, 13 reported that most of their friends are of the same sex, and 11 subjects reported having friends of approximately the same age. Concerning friends with intellectual disabilities, 12 subjects reported that their social circle included friends

with intellectual disabilities, and 13 reported having friends who do not have intellectual disabilities. Regarding this last data, it is possible to assume that part of the sample is not segregated from socialising with all people with and without intellectual disabilities, as they have friends with no such disability. However, one may ask, and consequently investigate, whether the friends without intellectual disabilities are in fact friends, or simply colleagues, or even psychotherapists who support them, since the 41 friends mentioned by the participants are in the following profile: nine are work-related, one is a sponsor, one is a dance instructor, and one is also a psychologist. In addition, all the participants reported that they go out on weekends in the company of family members. We also found that 14 also go out with friends, 12 with colleagues from leisure projects, nine with a girl-friend or boyfriend, and six reported going out with other colleagues.

According to the data analysis, a significant part of respondents admitted that access to employment contributed positively to expanding their circle of friends. Indeed, we found that nine of the friendships the workers reported are work-related, as reported in the following statements: "before the job, I had fewer friends" (P.4); and "before I used to be very shy, I could not speak properly to people. I met some at work, too" (P.17).

It is important to emphasise that the new relationships reported by the participants were not restricted to the workplace but expanded to encompass places outside the work environment. In this sense, we observed the following data: 14 of the workers participating in the survey reported going out with friends, especially on weekends, and 12 reported going with friends to places or activities of leisure. Another relevant piece of data concerns the fact that 12 of the participants also report seeking the support of friends, especially when they are bored and/or need some kind of help. Considering that the other friends reported by the workers are not working colleagues, it can be noted that some of the new friendships were made in the work context and grew beyond.

Regarding insertion and activity in society, which grew and improved due to the new requirements arising at work, we found, remarkably, that the subjects began to frequent and/or travel to new spaces. When asked about their relationships, particularly social ones, the participants mentioned certain places they supposedly went to regularly. In this regard, participation in religious cults, local parties and going shopping were the activities that more than half of the participants mentioned in common. Considering cultural leisure, especially theatre and cinema, 17 of the participants reported going to such places, usually in the company of family members and friends, including those from work. Thus, we note that friendships promoted and strengthened in the workplace, when adequately articulated or integrated with previously established relationships, help strengthen and consolidate self-esteem and improve the quality of life and standard of living considerably.

When interviewing the workers' families, it was possible to see a significant increase in friends. That is represented in the account given by the mother of a participant:

> I think her relationship at home and outside has changed a lot. Her circle
> of friends and colleagues has grown. (…) She has more friends now, espe-
> cially colleagues, but there are always those friends who are closer. (…) So,
> I can see that the work also made her circle of friends grow. (P.1's mother)

The mother of one participant (P.6) was concerned about her son's new relation-ships; though meant to provide the best development and protection, we must observe to what extent such concerns can generate conflict and even hinder the development of children.

Employers, co-workers and friends of workers with Down syndrome reported that they made new friends; many said they valued the relationship with these colleagues and stressed the importance of these friendships, which broaden their affective and so-cial relationships. Despite this, some showed that, in some cases, these new friends are limited to the workplace: "he made friendships at work, we met each other here actually. (…) sometimes it was at parties, but we hardly go out together in our daily routine" (P.2's friend). On the other hand, one of the employers reported:

> I think it has improved in terms of friendships and relations with other peo-
> ple. At first, I saw that she was very introverted and suspicious like I said
> before. And today, she is much more extroverted and interacts with others
> more easily. (P.3's employer)

Moreover, a third interviewee from the work team noted: "he made friends at work and sometimes he is invited to go to the movies with a colleague. He is happier. He has changed a lot since he started working" (P.9's co-worker).

The above quote (P.2's friend) suggests friendships are limited to the workplace, making us wonder if this is due to schedule incompatibility or a respectful and friendly interaction with these colleagues with intellectual disabilities that does not represent a bond of friendship. That does not exclude the importance of work for improving social life, as Pereira-Silva and Furtado (2012) pointed out, who claim interaction with other people is essential.

It is worth noting that the circle of friends did not change or grow for some partici-pants, even after they started working. However, it became clear in the testimonials that even when the circle of friends did not grow, their relationship with co-workers was not bad. As pointed out by the employer of P.8, the participants retained their significant ex-isting relationships, only adjusting the times when they go out and do things to the new schedules because of the working hours.

We also noted that some interviewees pointed out the influence of employment on their work relationships, even if such influence did not necessarily positively impact friendships. According to some reports: "he has friends at work. Sometimes it's not a friend, but a co-worker" (P.4's friend); "I have more colleagues at work, not more friends, I think because many people are still prejudiced about people with Down syndrome" (P.3).

This trend of responses is consistent with what Veiga et al. (2014) report:

> friendships (although some alumni have made more friends after entering the workforce) are few, neither truly close nor allowing for sharing and intimacy. Many are merely superficial and circumstantial, with each person giving little of themselves to the other. (p. 230)

Autonomy

In addition to the growing number of relationships and friends, employment can also be an important opportunity for people with intellectual disabilities to develop autonomy since this development is connected to the ideals of independence, freedom and self-sufficiency.

One of the necessary kinds of autonomy is related to political issues. It is interesting to note that 16 of the 20 participants vote in the elections. The fact that they choose their political representatives may indicate that they are aware of the need to choose from the different destinies of society. When we observe that democracy is under threat, not only in Brazil and that the number of people who stop voting is large, most of these participants vote in the elections is striking.

The autonomy achieved by entering the labour market grows: in the organisation of one's routine at home, by memorising the home-work route, when using money, and in daily life at work. The skills required from the subjects create challenges that can favour the development of initiative, accountability and independence, allowing them to plan, decide and take better care of their own lives, progressively decreasing the need for the help of third parties to perform their activities.

We emphasize that 19 of the 20 participants considered themselves more autonomous, self-assured and confident after being employed. In this sense, one of the reports is representative of this strong trend:

> my parents supported me, and I joined the labour market, and for me, it was very good because I became more mature, I grew up in the job and became more autonomous, independent. I can handle things on my own. (P.1)

Most participants answered that they help keep the house clean and organised; half of them usually cook, and few use the washing machine. According to their relatives, 15 of the participants help with household chores. These data indicate that workers' participation in household chores tends to focus on activities requiring less technical skill and planning, such as cleaning rooms and washing dishes.

Besides helping with household chores, we also found that many participants changed their self-care habits when they started working. More than half of them say

they have autonomy for self-care activities. Although this is a general trend, it is worth highlighting that it seems more prevalent in setting up a sleep schedule on weekends and choosing clothes. As for the choice and time of meals, most reported they did not have autonomy and followed the instructions of parents or mediators in those matters.

Despite these limits, we notice that performing the activities in which they gained autonomy is related to the significant development of independence and responsibility after they were employed. Many relatives report such gains. Two answers illustrate this perception: "I notice that she has become a more independent person, more autonomous... this I attribute to the work" (P.1's mother).

> She has amazingly grown since she started working, she became more autonomous. She can handle things on her own. She worked as a young apprentice before, and since then, it has been great. (...) Having a job is important for her in those issues that I talked about, developing her autonomy, her growth. (P.7's mother)

As noted, many of the workers with Down syndrome gained more autonomy in taking care of household chores and themselves, which is crucial for their own lives and family life. The interviewees were also asked about their leisure habits and the places they like to go to in their free time, also checking if this changed after they joined the labour market.

Participants seem to have autonomy about leisure time when deciding what to do in their free time and when friends invite them. This trend is similar to those indicated by Veiga et al. (2014), when they point out that workers have autonomy "in some issues related to household management of a more intimate and personal nature, what they want to do in their free time and what activities they want to do" (p. 209).

However, 17 of the participants reported that they need permission from their parents or guardians to go out and feel obliged to go with them when they go out, even against their will. It should be noted, according to Fernandes et al. (2014), that:

> the strategy of parental guardianship does not contribute to improving their quality of life. This strategy seems to be based mainly on placing impediments against them leaving the house without family control, which prevents or hinders autonomy when creating social ties and friendly or romantic relationships, including potentially significant and lasting ones. (pp. 209–210).

Two employers, two family members, two friends and one co-worker further indicated the issue of scheduling, commitment and sociability as essential skills and attitude changes that were developed in workers, suggesting that the job may have brought more confidence, responsibility and independence.

It should be noted that an employer indicated how the aspect related to learning hierarchical rules could be understood as a means that contributes to increasing respect

in relationships outside the family realm. Insertion in another context of social interaction, as is the case of work, sets the challenge for workers to understand the codes and rules in force in this context, which includes hierarchical relations, the difference between bosses and colleagues. If hierarchy as an end in itself is criticisable, it may be necessary as a means.

Approximately half of the participants use their money as they wish. The vast majority have a bank account and/or bank card, but only five deposit and withdraw their money. Some of the interviewees admitted that the autonomy gains are related to the remuneration for their work. For example, P.13's mother and a friend reported that the workers began to take better care of their own money and spend it better after they started working. Similarly, a friend of one of the interviewees pointed out the issue of income and purchasing power that employment introduced: "I think it's very nice for her to earn her own money, to be able to buy her things, go out, travel" (P.1's friend). Commenting on the same aspect, the mother of one of the workers reported the following fact:

> she can do things that probably we, with all the household expenses – I'm retired, he [her husband] is also, and I, working at school, know how it is? So she does things, and she can have her own life. In private classes, she wanted to study, but with a private teacher and at home. So the teacher comes and gives her lessons here, and she pays for them. She pays for them herself when she takes courses at the National Industrial Education Service. When we are no longer here, that gives us some security because she has her own job, and her sister will be there for her just as her support network, right? (P.19's mother)

Admitting the pros and cons that wage autonomy has brought to the lives of her children, one of the mothers also highlighted the following aspect:

> There is the upside and the downside. The upside is that she has initiative. She can go out and buy her things, travel. The downside is that she questions me when I deny her something; she says, "I earn my money". (P.16's mother)

Therefore, money is a significant element in the workers' lives. It represents a way of securing their autonomy (either through purchasing power or the possibility of helping with household expenses). It stands out from the aspects discussed so far. It seems to represent a relevant challenge that those subjects are able to use their financial resources as autonomously as possible and with the minimum necessary support.

These gains can be seen through effective recognition directed to people with disabilities, either by their family members or by friends or other people workers consider important. The analyses by Pires et al. (2007) confirm that employment can positively influence these workers' self-esteem, autonomy, and social recognition for how they are seen by others and by themselves.

The issue of mobility raises interesting discussions about the development of autonomy after employment. Regarding the ability to get around alone (transportation), two participants and a mother reported: "I always go by car (…) if they let me go to work alone, I would be able to come back" (P.12). Another participant said:

> I go out alone, sometimes I go out with my mother, too. Because my mother wants me to travel with her; sometimes she wants to travel with me, so we do it; sometimes I can't go because I am working, or because of my social group, Simbora, gente! (P.14)

About that, the mother of one participant also said:

> he could be more [independent]. (…) He could go swimming, for example; he could take the bus. But when he comes back in the evening, he is tired. I wish he were more autonomous. Then the guy says, "you should ride the subway more". But to go where? Does he have a girlfriend, and that is why he needs to ride the subway? No, he doesn't. (P.15's mother)

Most participants do not have the autonomy to get around alone. According to friends, only three of the participants go to work or other places they need to, alone; eight go out at night, but only with friends, which suggests little autonomy to get around. This piece of data is reiterated by the relatives of the participants, which shows that only three of the interviewees go to work or other places alone. Nine participants go out at night, usually with a leisure group mediator.

We notice how the issue of mobility becomes very important for both the workers and their families. Take as an example P.13, who, once he started working, became more autonomous in managing money, mobility, dressing and feeding himself, although he still does not leave home unaccompanied for anything. That brings us to why this autonomy gain seems more delicate or even more complicated.

Sometimes, families feel that their children with Down syndrome are less autonomous than they consider themselves, as the family always insists on accompanying them on their routes. Despite the various gains in autonomy mentioned by the interviewees, the issue of mobility still needs to be highlighted, perhaps because it implies a greater separation between workers and their families and caregivers, mainly because they put themselves in a vulnerable situation when getting around a large city.

To compare the different types of autonomy, we calculated the indicators for each of the evaluated and presented them in Table 1. These indicators were calculated based on the various aspects analysed, ranging from 0 to 1.0: the closer to 1.0, the greater the autonomy.

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Autonomy	Financial	Getting around	Self-care	Leisure
Media	0.7	0.3	0.7	0.6
Standard deviation	0.3	0.3	0.2	1.1

Table 1 *Mean scores and standard deviations of the various forms of autonomy of participants*

According to the data in Table 1, participants have good autonomy in handling their finances, self-care and leisure, but little autonomy in getting around.

To know if there is a relationship between autonomy for mobility and the HDI of the participant's area, we calculated Spearman correlations between this autonomy and the salary earned in the job. We found a significant correlation between autonomy for getting around and the HDI ($r = -0.50$; df 18, $p = 0.03$), suggesting that the lower the HDI of the district where the participant lives, the greater the autonomy to move; conversely, the higher the HDI, the lower the autonomy. Indeed, P.9 and P.14 have the highest indicators of autonomy. Both have life stories showing financial struggle; this seems to indicate that when the family is financially stable, they may overprotect their children with disabilities, thus preventing them from developing this type of autonomy. In addition, we also found a significant correlation between autonomy for getting around and salary *($r = 0.45$; df 18)*: the higher the salary, the higher the degree of autonomy for getting around.

Wellness and Life Projects

Besides the circle of friends and autonomy, joining the labour market can significantly affect the wellness of people with Down syndrome. We present below indicators from the interviews showing that working represents an achievement for these people, a reason for personal satisfaction, and how much this impacted their wellness.

Initially, we point out that in the answers to the questionnaires, all participants think they are happy, well-disposed people who like their lives. Furthermore, 19 of them say they are satisfied with themselves and think that the job has made them happier. Amongst the family members, the number is lower, but still, 12 family members think that the workers are happier after being employed. That shows that, generally, joining the labour market brings positive consequences for the feeling of wellness of the workers.

The testimonies indicate that many family members perceive the gains related to wellness, especially those related to being useful and the social inclusion of workers. These are crucial aspects for implementing an inclusion policy that goes beyond the insertion of people into jobs, thus allowing employment (and all the increased autonomy and engagement related to it) to promote greater social participation.

Another aspect related to the well-being of the interviewed workers is the way they see their present life compared to their prospects. This prospect raises from various visions, such as life plans, projects, dreams, desires and goals. In this sense, we notice that these workers have different ambitions, some of which have changed after being

employed. Participants most often aim to: earn more, have their own home, get married, date and have children. These examples suggest no differences in the aspirations commonly attributed to young adults, as our participants can be described, according to their age.

Therefore, we can conclude that most have dreams and expectations instead of showing resignation as everyone does. In this regard, the answer given by P.1 that he wants a "more hectic" life strikes us, as it suggests both a feeling of monotony, possibly due to the few opportunities given to people with disabilities, and also their capacity for perception and criticism. Except for two participants, who think they will not be able to meet these expectations, and another one who thinks they already have everything they need, everyone believes they will be able to achieve what they expect for a better life.

According to the interviews with family members, 10 participants want to get married. In the accounts, two mothers of workers also reported that, after they started working, they began to make plans, set goals and consider new projects for the future.

In the described reports of some participants, we can detect how inclusion in work can rescue social participation in the sense of broadening their horizons and developing their dreams and expectations. We can identify a complaint that the company where they work does not allow them to perform other roles, even if those roles are part of the industry where they operate. From the point of view of professional inclusion, companies could rethink their practices and adopt actions to become even more inclusive, accepting the challenges that arise as the desires and ambitions of the subjects, who also become workers, grow.

One of the survey participants was dismissed while we were collecting the data. He said he considered himself happier when working and reported that being dismissed felt like a "kick in the stomach" (P.4).

Therefore, insertion in the labour market allowed the participants to feel better about many aspects of their lives. In cases where there was not much influence from the job, we noticed how the participants and the other assessed interviewees were already happy with themselves and their lives, so the job did not bring any visible negative or positive consequences. The negative points of having a job pointed out in three statements seemed to be related to routine and schedules, which is part of the working conditions of all people and constitutes legitimate frustrations, but not specific to the inclusion of people with disabilities.

Final Considerations

The data found in the reported research confirm a large part of the data obtained by the research by Veiga and Fernandes (2014).

We note that as people with Down syndrome joined the world of work, their social and affective relations were enriched and influenced, as highlighted by Leite and Lorentz

(2011). In certain situations, encounters and bonds have become more solid friendships. However, we also observed reports where such ties were based on a relationship of affection and respect between colleagues. These observations were confirmed by 19 of the 20 participants in the survey, who reported being satisfied with their friends.

In some accounts, we noted a degree of reluctance or resistance on the part of some colleagues regarding workers with disabilities; however, as another relevant piece of data, it was possible to observe the engagement of other colleagues, a determining fact in the process of physical and social integration of employees in the workplace.

Many of the interviewees reported that the subjects developed autonomy due to their insertion into jobs. As we observed, 19 participants considered themselves more autonomous, secure and confident to deal with everyday situations. The data obtained by applying the questionnaires indicated that work brought about greater financial independence.

According to the accounts of family members, most participants in the research cooperate with household chores by performing tasks that require less planning and technical skill. According to the data, we also found a significant correlation between the workers' autonomy to get around and the HDI of the place where they live: the lower the HDI where they reside, the higher their degree of autonomy to move. Most of the accounts also pointed out that employment resulted in increased well-being for workers with Down syndrome regarding the feeling of happiness and social participation and the self-perception of being helpful, accepted by peers, and able to contribute to the family to plan for the future.

Having a job increased self-esteem, autonomy, and wellness of the workers with Down syndrome interviewed in this survey due to the new experiences afforded by the jobs, which was also found in the research by Veiga and Fernandes (2014) and Leite and Lorentz (2011). We emphasise that the support of family, colleagues and bosses and previous training are crucial for the inclusion of these people, made possible and realised by access to employment, a fact which reverberates into other areas of social life, which is highlighted by Pereira-Silva et al. (2018).

Finally, we emphasise the importance of developing policies aimed at inclusion to strengthen actions that favour the admission of people with disabilities into the labour market, despite possible criticism of the capitalist mode of production and the exploitation inherent in this regime.

Translation: Alex Sandro Corrêa, José Leon Crochick, Rodrigo Nuno Peiró Correia and Fabiana Duarte de Sousa Ventura

References

Alves, L., Corrêa, A. S., Correia, R. N. P., & Ventura, F. D. de S. (2019). Autonomia e bem-estar após o ingresso no mundo do trabalho. In J. L. Crochick (Ed.), *Inclusão profissional de trabalhadores com deficiência intelectual na cidade de São Paulo* (pp. 93–127). Benjamin Editorial; FAPESP.

Crochick, J. L. (Ed.). (2019). *Inclusão profissional de trabalhadores com deficiência intelectual na cidade de São Paulo*. Benjamin Editorial; FAPESP.

Crochick, J. L., Kohatsu, L. N., Dias, M. A. De L., Freller, C. C., & Casco, R. (2013). *Inclusão e discriminação na educação escolar* (1st ed.). Alínea Editora.

Fernandes, L. M., Veiga, C., & Silva, C. (2014). Autodeterminação e vida independente. In C. Veiga & L. M. Fernandes (Eds.), *Inclusão profissional e qualidade de vida* (pp. 189–210). Edições Húmus.

Leite, P. V., & Lorentz, C. N. (2011). Inclusão de pessoas com síndrome de Down no mercado de trabalho. *Inclusão Social, 5*(1), 114–129.

Pereira-Silva, N. L., & Furtado, A. V. (2012). Inclusão no trabalho: A vivência de pessoas com deficiência intelectual. *Interação em Psicologia, 16*(1), 95–100. https://doi.org/10.5380/psi.v16i1.23012

Pereira-Silva, N. L., Furtado, A. V., & Andrade, J. F. C. M. (2018). A inclusão no trabalho sob a perspectiva daspessoas com deficiência intelectual. *Temas em Psicologia, 26*(3), 1003–1016. https://doi.org/10.9788/TP2018.2-17Pt

Pires, A. B. M., Bonfim, D., & Bianchi, L. C. A. P. (2007). Inclusão social da pessoa com síndrome de Down: Uma questão de profissionalização. *Arquivos de Ciência da Saúde, 14*(4), 203–210.

Veiga, C. V., & Fernandes, L. M. (Ed.). (2014). *Inclusão profissional e qualidade de vida*. Edições Húmus.

Veiga, C. V., Fernandes, L. M., & Saragoça, J. (2014). Participação comunitária e satisfação com a vida. In C. V. Veiga & L. M. Fernandes (Eds.), *Inclusão profissional e qualidade de vida* (pp. 211–241). Edições Húmus.

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Workers With Down Syndrome · Alex Sandro Corrêa, José Leon Crochick, Rodrigo Nuno Peiró Correia & Fabiana Duarte de Sousa Ventura

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Varia | *Varia*

"The People Turn it Off and Go Out Looking for Fado" — Radio and the Fado Resistance to the Estado Novo in the 1930s

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Abstract

Far from its current consecration and even before its domestication by Salazarism, fado went through dilemmatic phases throughout its existence. Among them are the early times of its mediatization, particularly the complex relationship with radio in the 1930s, with the Estado Novo and class prejudices attempting to ostracize fado or, at least, to stop the national legitimization of urban popular culture. The tensions that already surrounded fado were renewed and sharpened in the simultaneous context of the stabilization of the dictatorship and the implementation of radio in Portugal, placing the new means of sound diffusion in the centre of symbolic struggles around the "national song". Involving dilemmas between stigma and fado legitimation, between its origin and propagation, between public diffusion and aesthetic or moral control, a connection between radio and fado was made, where several social actors positioned themselves, with different goals and strategies, and in which questions of programming, discursiveness and social status were tackled. This article aims to identify this set of interactions throughout the 1930s. It tries to understand how the establishment of the radio industry, with its various stations and nuances, became a stage and participant in a cultural process that, in some aspects, already preceded it. The research is based on contemporary press publications, specifically fado newspapers (*Guitarra de Portugal, Canção do Sul*) and magazines focused on radio (*Rádio Semanal, Rádio Revista, Boletim da Emissora Nacional, Rádio Nacional*).

Keywords

radio history, fado, Estado Novo, 1930s, press

"O Povo Desliga, Vai à Procura do Fado" — A Rádio e a Resistência Fadista ao Estado Novo na Década de 1930

Resumo

Muito longe da consagração atual e mesmo antes da sua domesticação pelo salazarismo, o fado atravessou fases dilemáticas da sua existência. Entre elas, estão os tempos iniciais da sua mediatização, em particular, as complexas articulações com a rádio na década de 1930, com o Estado Novo e os preconceitos de classe a tentarem ostracizar o fado ou, pelo menos, travar a legitimação nacional da cultura popular urbana. As tensões que já antes rodeavam o fado renovaram-se e agudizaram-se face ao contexto simultâneo de estabilização da ditadura e de implantação da rádio em Portugal, colocando o novo meio de difusão sonora no centro das lutas simbólicas em torno da "canção nacional". Envolvendo dilemas entre o estigma e a legitimação fadista, entre a sua origem e a propagação, entre a difusão pública e o controlo estético ou moral, constitui-se uma zona de articulação da rádio com o fado onde diversos atores sociais se posicionaram, com diferentes objetivos e estratégias, e em que se jogaram questões de

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programação, discursividade e status social. O objetivo deste artigo é identificar esse conjunto de articulações ao longo dos anos 30, tentando perceber de que maneira a formação do campo radiofónico, com as suas várias estações e matizes, se tornou palco e participante num processo cultural que, em alguns aspetos, já o precedia. A pesquisa baseia-se na imprensa coeva, especificamente nos jornais de fado (*Guitarra de Portugal*; *Canção do Sul*) e nos periódicos dedicados à rádio (*Rádio Semanal*; *Rádio Revista*; *Boletim da Emissora Nacional*; *Rádio Nacional*).

PALAVRAS-CHAVE

história da rádio, fado, Estado Novo, década de 1930, imprensa

Unlike the deference with which fado is treated today as part of the Portuguese cultural heritage, this musical genre went through periods of intense symbolic struggle in the public space, navigating through social tensions and political projects.

An especially significant period was the one that corresponded to the first stages of the implementation of radio, from the beginning of the 1920s, but particularly focused on the 1930s — with the creation and consolidation of broadcasting stations, the popularization of radio listening, and the press' attention on the new medium.

Crucial studies for the history of fado in the 20th century (Brito, 1999; Carvalho, 1994; Nery, 2012; Sucena, 1993) mention in a prominent manner the appearance of radio, underlining its character as a divulging and diffusing mechanism, which changed the framework of music's activity, provided a wider audience for fado and contributing to the professionalization of fado singers (Carvalho, 1994, pp. 84, 94).

In these works, it is pointed out that many broadcasting stations used fado as a strategy to capture the popular audience, as well as the ambivalence of the official radio of the Estado Novo (Nery, 2012, pp. 254, 257). In historical studies about radio, there are also mentions of fado, especially in the relationship with small stations in Lisbon (R. Santos, 2005), but also with the state radio (Ribeiro, 2005).

It is our understanding that the link between fado and radio in its implementation phase deserves a degree of detail in which three axes are highlighted: the variety of modalities that serve the diffusion of fado through radio; radio as a platform for conversations on fado; and the development of radio itself as a propeller of discussion about fado and the symbolic struggles around it.

These allow us to perceive the radio of the 1930s as an apex where two contradictory forces from previous decades converge: on one hand, the gradual expansion of fado beyond the original limits of Lisbon's neighbourhoods and popular classes, along with its conversion into a spectacle and a consumer product; on the other hand, the non-acceptance, by important sectors of the dominant classes, that a phenomenon coming from the impoverished urban culture, and with links to social marginality, could become a musical expression recognized in the public space and legitimized at a national level.

To delve into the intersections between fado and radio, we focus on two segments of the 1930s press — fado and the radio — compiling the references to radio in fado newspapers and the allusions to fado in radio newspapers. In the first case, we focus on

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the fortnightly *Canção do Sul* and *Guitarra de Portugal*, which cover the whole period. In the radio segment, we used the *Boletim da Emissora Nacional* (1935–36), the magazine *Rádio Nacional*, which succeeded it as the state radio entity from 1937 on, and the independent publications *Rádio Semanal* (1934–40) and *Rádio Revista* (1935–36).

The Initial Mediatization

In Portugal, radio was born almost simultaneously with the dictatorship that would lead to the Estado Novo, and it is fair to consider that its implementation period lasted until the 1940s, a decade in which the domestic possession of a radio device is massified (only then exceeding 100,000 devices across the country). This period can, in turn, be divided into four stages, taking into account some milestones in radio history that emerge in its relationship with fado:

1. 1924 to around 1930 corresponds to the first generation of small stations, where broadcasting follows the concert logic;

2. around 1930 to 1935, new stations truly began the structuring of the radio field, with regular broadcasts, creation of programs and diversification of genres;

3. 1935–1941, the field is redesigned with the definitive functioning of a state actor, Emissora Nacional;

4. 1941–1950 Emissora is headed by the director of the Secretariat of National Propaganda, António Ferro, a direct instrument for the "politics of the spirit" (a stage that cannot be developed in this text due to space constraints).

Before radio, fado was already a musical practice with a certain number of mediations that fed its expansion. This was the case of the recordings that, between 1904 and 1915, targeted a middle-class audience, as well as other beginnings of a cultural industry around fado, which translated into scores for piano and singing, as well as the sale of brochures with lyrics — products aimed at educated consumers and for the recreation of fado songs at home. It should also be noted the intermediary role that, for this public, was played by the *teatro de revista*. Since the end of the 19th century, this theatrical genre included fados, lightening their forms and having them accompanied by orchestras, to bring them closer to the Lisbon middle classes and to integrate them in their cultural consumption. Joaquim Pais de Brito (1999) highlights this social stratum that, although "imprecise in its outlines", becomes relevant in the relationship with fado and is composed of a small and middle bourgeoisie with the means to attend shows and to acquire successive technical apparatus, such as the earlier record players (*grafonola*; p. 28).

But, when the radio first appeared, beyond taverns and bars — located in poor neighbourhoods and the natural home of the fado practice for decades — the intermediate social strata of Lisbon only had contact with fado in halls and theatres. For this public, since the beginning of the century, a network of cafes and beer houses had been forming, offering fado performances. Those to whom social status and respectability concerns prevented them from going to the taverns of Alfama or Mouraria, could now enjoy fado in environments where composure was maintained (Nery, 2012, p. 219), some of them in more reputable parts of the city.

Since the turn of the century, the capital was marked by accelerated growth and thus social differentiation intensified. The working population attracted by the expansion of the port and living in precarious areas increasingly contrasted with the orderly well-being of the avenues and new parts of the city, but also crossed paths with the petty bourgeoisie and service employees, shopkeepers and cashiers, who in some neighbourhoods coexisted with the lower classes, but aspired to distinguish themselves from them and professed other moral standards (Rosas, 2018).

It is in the light of these social contrasts and symbolic conflicts that we should read the stigmatizing classifications that António Arroio or Albino Forjaz Sampaio made of fado in the 1910s; and who in the mid-1920s frequently and controversially returned to the pages of the fortnightly *Guitarra de Portugal*, directed by the fado poet Linhares Barbosa. The citation of articles published by "detractors" in other newspapers (some of them "provincial") and the responses by fado hosts live on many editions from 1925. The divergences could also concern those within the fado community, as happened in December 1926 regarding the operetta *Mouraria*, making it clear in the articles in *Canção do Sul* that a crucial concern for the genre and its practitioners at the time was the search for respectability, for which they often invoked old historical contacts with the aristocracy.

A compilation of external criticism of fado would appear in the volume published, days before the military coup that established the dictatorship, by the Porto intellectual José Maciel Fortes (1926), for whom fado is the "favourite song of harlots and (…) of the lowest social classes" (p. 99) and "is nothing but a vagabonds' song, a hymn to crime, an ode to vice" (p. 71). This discourse, which disqualifies fado in terms that are simultaneously moral, classist and artistic, points to the kind of hostility that existed at the time when broadcasting took its first steps.

But the refusal to accept fado as the "national song" is at that moment also based on historical-racial reasons — pointing out fado as derived from a "negroid song form" (Fortes, 1926, p. 45) in an attempt to delegitimize it in line with emerging fascist theses. Fortes' (1926) criticism is directed at the reception of the genre in the classes seen as respectable, as well as at the publishing houses' trade as a means of propagation. As a Lisbon trend that spread progressively throughout the country, fado would not yet live, however, in the soul of the people of all the provinces, argued the author.

It was precisely in the middle of that decade that the first generation of radio began with regular broadcasts from small stations. According to Rogério Santos (2005), in this period, the prevalence was on the transmission of classical music concerts, with singers and instrumentalists in the studio or with "*grafonola* concerts", sometimes combining classical music with moments of poetry, humour, or other musical genres. It was a model that tended towards erudition, put into practice by stations whose owners belonged to business or military circles (R. Santos, 2005, pp. 95–96). Its beginning happened under a concept that saw radio also as a "powerful educational factor"[1] (Neves, 1925, as cited in R. Santos, 2005, p. 67).

In this phase, fado appears sporadically in the middle of some transmissions. One of the first was a performance by Alfredo Marceneiro, accompanied by guitar and viola,

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[1] Hermano Neves, president of the TSF (*Telefonia Sem Fios*) Portuguese Society, in 1925, for *Rádio Lisboa Magazine*.

in March 1925, at the P1AB station, within a concert program dominated by classical music[2] (R. Santos, 2005, pp. 229–230). Through the daily press, Rogério Santos identified several occasions when fado sessions were broadcasted in the following years: a night of fados organized by *Diário de Notícias* in April 1927 and broadcast by the CT1AA station; the broadcast of fados and *guitarradas* from the Café Mondego, in 1928, by the CT1BM station; a concert organized, in January 1929, by the violist Mário Marques and the guitarist João Fernandes, with fados of his and Armandinho's authorship, sung by Ercília Costa, also broadcast by the CT1AA (R. Santos, 2005, pp. 242–243).

Although fado was very much a minority in the intermittent radio broadcasting of this phase, it seems that several forms of connection between fado and radio then began to emerge. However, on its eve, this connection was just like radio itself. This is suggested by issue 44 of *Notícias Ilustrado*, on April 14, 1929, entirely dedicated to a "great inquiry on fado", where the mediation of the record and of "gramophony" is much more present than TSF. In the fado newspapers, references to radio are practically inexistent until the end of the 1920s.

What stands out, however, in this phase is the participation, small but apparently odd, of a popular musical form within an erudite and educational concept of radio, which complicates a linear reading of the relationship at the time between questions of status and social class with fado.

1930–1935: Fado and the Structuring Process of the Radio Circuit

The early 1930s is pointed out as the period when a second generation of radio stations was born and where there is a transition from the musical season model to a radio structure of programmes and items, with more regular broadcasts and a diversification of genres (R. Santos, 2005). Several of these small broadcasting stations are created through the initiative of Lisbon traders, who are, therefore, closer to popular classes, accumulating directive and technical functions in the radios and trying to establish a more permanent link with collaborators.

It is also in the first half of this decade that fado claims a more frequent presence in radio, examples of which are Rádio Colonial (CT1AA, coming from the previous phase), in which broadcasts led by the violist Amadeu Ramin were promoted "on an experimental basis", as early as 1930 (Sucena, 1993, p. 201), and Rádio Luso, which since 1932 is characterized by the diffusion of fado and by expressing positions favourable to fado (Neves, 2017, p. 20).

The contemporary press indicates that also at Rádio Graça, created in 1932, there were fado broadcasts, at least since the beginning of 1933[3]. Also, in relation to Rádio Condes, there are references to fado performances, whose initial date is not possible to specify, but prior to 1935 (*Canção do Sul*, June 16, 1935). There is, therefore, a set of small broadcasting stations in Lisbon, with a restricted geographical scope of diffusion,

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[2] Referred to in the *TSF* magazine in Portugal.

[3] The first reference to fado broadcasts in Rádio Graça is seen in *Canção do Sul*, on February 1, 1933.

where fado was heard in the first half of the 1930s. But it also reaches a station with other means and closely associated with the regime, Rádio Club Português (RCP), whose fado broadcasts were first found in the press in 1934 (*Guitarra de Portugal*, May 31, 1934).

It is difficult to understand, in the consulted sources, what the actual frequency of fado was in the stations mentioned, but what there is no doubt that the relationship between the two was close, this being a sign of the pluralization of forms through which radio appears to articulate with fado. These include several ways of diffusion besides the record. On the one hand, there are the transmissions from places where fado is shown, which can, in fact, integrate the radio trump card in its promotion to the public (as in the advertisements in which the Café dos Anjos boasts of "irradiating through TSF"; *Guitarra de Portugal*, November 14, 1933). On the other hand, there is the development of fado studio performances, some of which end up being part of agreements established with the fado newspapers, but which in general seem to be part of a professionalization of fado artists (which started in 1927 with the decree that obliged them to have an artist card to perform in public)[4], who try to incorporate the radio stations in their performance circuits and as a means of dissemination.

There are other signs of a developing connection, such as fado lyrics with allusions to radio, rare but curious, of which some of Álvaro Fialho's verses that use radio as a metaphor are an example:

> tender radio, I have broadcasted/ From my heart to yours/ (...)/ An hertzian wave/ It ran across all the space/ In a mindless rush/ From my heart to yours/ (...)/ If the reception was good/ If the connection was not lost/ Why has your heart/ Still not responded? (*Guitarra de Portugal*, November 30, 1930)

And then there are the advertising campaigns with which the device brands appealed to the fado-loving audience and which included the use of faces like those of Berta Cardoso and Ercília Costa, fundamental names in the fado scene at the time. These ads proliferated in 1934 and are another indication that fado lovers were not restricted to the lower classes, for whom the acquisition of a radio device was at that time unaffordable. The state radio, which in that same year started the experimental broadcasts, would launch in 1935 a campaign to support the purchase of devices at reduced prices, but without managing to massify, in the short term, access to the radio idealized as a propaganda instrument of the regime[5].

What the new radio context seems to have provoked, simultaneously with the stabilization of the dictatorship in its *Estado Novo* form from 1933 onwards, was a renewed and virulent impetus in the discourses against fado, where its broadcasting as a problem emerges very clearly. The year 1934 also stands out in this aspect, when several articles

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[4] This regulation of fado by the new dictatorial regime, which was intended to control performances and moralize its practices and contexts, ended up working as another incentive for fado singers to seek a professional path, as pointed out by Rui Vieira Nery (2012, p. 239).

[5] In 1933, there were only 16,000 devices registered across the country. In 1935, there were 40,000. In 1937, the figure rose to 69,000.

in *Diário de Notícias* are well-received, thus this reaction in the fado press, which does not fail to identify the motivation for criticism: "the Gordian knot revolves around TSF (...) it was a pity that only fado hurt his eardrums"[6] (*Canção do Sul*, August 20, 1934, p. 1). It was not by chance that the attacks intensified after April, when Emissora Nacional started broadcasting, still in an experimental manner.

In this "campaign" against fado, the daily *Revolução Nacional* also takes on a prominent role, where it laments "hearing on several Portuguese stations (even the national one) Maria dos Quintalinhos and Micas singing the fado of the shameless" ("Relice Nacional", *Guitarra de Portugal*, September 15, 1934, p. 11). The action of this publication, a newspaper close to national syndicalism, a movement of fascist nature that Salazar had just neutralized as an internal opposition to the regime, suggests that various factions of the game of balances that Salazarism had turned into were also distancing their own ideologies from fado[7]. In this stage, one of the main discursive lines is still the insistence on associating fado with prostitution and the marginality of the Lisbon milieus, as a way to delegitimize its broadcasting and oppose its national expansion.

The politicization of the connection between radio and fado is, therefore, another axis of their articulations that deepen in the first half of the 1930s. But an additional aspect of this same articulation lies in the fact that radio also became a platform for political combat around fado.

Naturally, the discourses against fado tried to use radio as a means to criticize it, but the small stations that dedicated themselves to the diffusion of this musical genre were of no use. Therefore, RCP is taken as a possible base for the condemnation of fado, through that radio genre, then notable, that was the lecture (*palestra*). This is what happens in May 1934, when the RCP broadcasts a *palestra* characterized as "insulting and offensive to fado" by *Guitarra de Portugal*, which in turn reacts through RCP itself, organizing, in association with the daily newspaper *O Século* and a brand of appliances, two "response" hearings in June, where Maria Albertina, Maria do Carmo and Filipe Pinto perform (*Guitarra de Portugal*, May 31, 1934, p. 7, and July 30, 1934, p. 2). One of the lyrics sung by Maria Albertina was an advertisement for the sponsoring brand, another sign of the paths that the fado professionalism was testing in cooperation with the radio industry. The ambivalent position of RCP, between its commitments to the regime and the commercial nature that aimed to expand the audience, would have provided it with a stage for this dispute.

We can see, therefore, that another of the connections that develop in this phase between fado and radio is the fact that the fado reaction also uses broadcasting stations, in actions understood by fado artists themselves as a policy of "propaganda" in favour of fado. This disposition doesn't start with the RCP contention because, before that, the radio industry was already being seen by fado sectors as a space of affirmation in a context of a symbolic struggle. An example of this is a news item from *Canção do Sul* in early 1933:

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[6] Referring to a piece from *Diário de Notícias* titled "Triste Fado" (Sad Fado), anonymous but attributed to that publication's director.

[7] With Manuel Múrias as diretor, *Revolução Nacional* was published between March and August 1934.

new players are coming in, with which fado feels refreshed and ready to con-
front the insane wave [of hate attacks]. Now it was the group Leais Fadistas
(…) holding a fado session at *Rádio Graça*, so well received by the listeners
that telephone requests were constant. (*Canção do Sul*, February 1, 1933, p.
1)

The defence and promotion of fado within radio itself also involved the broadcast-
ing of lectures, such as those that the journalist and poet Armando Neves gave on Rádio
Luso in 1932 (Neves, 2017, p. 20). But it is in 1934 that this relationship was structured
in a more institutional way, not only with the multiple initiatives of the fado press itself in
promoting radio auditions[8], but also with the establishment of privileged links between
newspapers and broadcasting stations, namely of *Canção do Sul* with Rádio Graça and
Rádio Condes, and of *Guitarra de Portugal* with Rádio Luso, where Linhares Barbosa was
invited to direct the fado section (*Guitarra de Portugal*, December 8, 1934, p. 3).

Regardless of the sympathy that fado might have gained in the middle classes, what
united the fado singers to the small local radios and their audience from the popular
districts was, to a great extent, a socially coincidental world. The owner of *Rádio Graça*,
Américo Santos, who was in charge of the technical aspect, programs, and voiceovers,
was a modest bookkeeper, therefore close to the original professions of the *Ídolos do Fado*
(Fado Idols) listed by Victor A. Machado (1937): clerk, typographer, upholsterer, mechan-
ical locksmith, railroad worker, electrician, shop clerk and bricklayer. Among women fado
artists, there were seamstresses and factory workers, but most were not even assigned a
profession. This social context is frequently associated by the fadophile discourse to the
disregard of the genre: if fado is not artistically recognized, it is "because it is poor, gener-
ally disseminated among the children of the people" (*Canção do Sul*, June 16, 1934, p. 3).

In this sense, the broadcasting of fado corresponds to the projection of the popular
urban classes in the public space. It is not only about the spreading to other regions of the
country, a movement in which radio is part of a wider diffusion system[9]. What was also
at stake with the access of fado singers to radio stations was a symbolic dignification of
figures "of the people", and of urban popular culture, a dignification that was all the more
widespread, the more prestigious was the radio's status and the scope of its diffusion.

After 1935: Emissora and the National Song

When, in August 1935, Emissora Nacional began its regular broadcasts under the
direction of Henrique Galvão, there was an ideological program that included the educa-
tion of "good taste" in music aimed to "exert a profound action" especially on the "work-
ing and popular classes"[10]. This strategy — constrained by reduced financial means —

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[8] Just like *Guitarra Portugal*, so did *Canção do Sul* does it on several occasions.

[9] The radio came to participate in the geographical expansion of fado that the critical discourses already identified in the
previous decade and that is also fed by "fado embassies" to the province, noted in the newspapers between 1930 and 1934.

[10] Henrique Galvão's interview in *Rádio Semanal*, published in *Boletim da Emissora Nacional*, no. 1, August 1935, p. 100.

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provoked, however, frictions in Emissora and led to accusations of cultural vulgarization directed at the director (Ribeiro, 2005, p. 119), tensions that referred, after all, to "the central issue of the binomial between high culture and popular culture" (Moreira, 2012, p. 64) that was at the heart of the Estado Novo's ideology.

Harassed by sectors of the regime and excluded by the Secretariat of National Propaganda from the Portuguese "soul", fado was ideologically conditioned on official radio. But it began to have a regular space as of November, when 20-minute broadcasts were made live from Retiro da Severa on Sunday and Thursday nights (*Boletim da Emissora Nacional*, no. 4, November 1935). In that month, fado occupied 2.6% of the musical broadcasting time (1 hour and 37 minutes in total) against 6 hours of regional music (data published by *Boletim da Emissora Nacional*). The Emissora's programming concentrated on high culture (more than 80% of the music). It showed that the strategy to "approach the popular classes with good elements of musical culture" (*Boletim da Emissora Nacional*, August 1935, p. 100) consisted mainly in offering them cultured forms, sometimes in more accessible guises.

The predominance of these cultural forms made Emissora a markedly symbolic space for the upper classes. Female participation, for example, was led by erudite theatre actresses, poets, lyric singers and instrumentalists (in addition to speakers who addressed "feminine themes"), resembling, in fact, a similar classist character of the pre-1930 generation of stations.

In this scenario, fado broadcasts are understood above all as a pragmatic attempt to co-opt the popular classes, with Henrique Galvão intuiting a dialogic character of radio and the possible reactions of the public. For the director of Emissora, the popular public would not accept

> exclusively erudite programs whose subject matter is beyond the reach of their sensibility (...) and even less will they accept them broadcasted having the possibility to turn the knob of their apparatus and search in the private stations for the light music they like.[11] (Galvão, as cited in Moreira, 2012, p. 64)

But the introduction of fado can also be understood as an awareness that its audience already touched the middle classes, as Galvão alluded to device owners who would ask a fee of 6 *escudos* to listen to it (*Boletim da Emissora Nacional*, August 1, 1935, p. 98).

In any case, the Emissora broadcasts provided a new radio context where two aspects are worth noting. Firstly, giving fado singers a regular space on the official radio, and even more so within a radio model of legitimate culture, could only be seen as a form of legitimization of fado and therefore contained considerable symbolic potential. Secondly, and as a refusal of that same legitimization, the hostile interventions to fado from the intellectual nuclei of the Estado Novo were exacerbated, and, once again, the radio space became the stage for its own struggles in this regard.

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[11] Letter to the minister Duarte Pacheco.

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Faced with the new circumstance that is the existence of a state broadcasting station, the discourse of the intellectuals of the regime is not totally homogeneous, namely in what concerns the solution to the problem of fado radio broadcasting. One current, of which the journalist Augusto da Costa (1936), a native of Lusitanian Integralism[12], is a member, simply defends its prohibition:

> we are convinced that it won't be long before all broadcasting stations, state or private, are entirely at the service of the Nation, being able to transmit, both in words and music, only that which truly serves the Nation. Will fado disappear from radio broadcasts? This is the way it must be. (*Boletim da Emissora Nacional*, no. 7, p. 90)

It was a matter of defending the imposition of state power to all radio stations in the name of a national authoritarian policy, and not only to Emissora Nacional, but one cannot dissociate such a position, in early 1936, from the role that official radio had assumed in the diffusion of fado. It was not the first time, by the way, that integralist voices proposed to simply extirpate fado from Portuguese cultural practices[13].

Another current can be identified in the series of eight lectures given by Luiz Moita on fado, between April and August 1936, at Emissora Nacional. An intellectual of António Ferro's circle and, therefore, a supporter of the construction of a certain canon of popular music of rural inspiration as part of the Estado Novo "politics of the spirit", Moita dedicates the lecture of July 7 to the radio. After describing the mixture of shouts, smoke and fado ("there's the little device on"; Moita, 1936, p. 165) that in Lisbon comes from the taverns to the streets, he thus concludes his thesis:

> I am not going to affirm, because it would seem crazy to many, that we promote, in the broadcasting stations, the abrupt suppression of fado. (...) I agree that we should give the idolaters - the last blessings of a pagan cult with no tomorrow, the faculty of dividing their "broth of culture" (...) But we should stop there... In no case should we allow, I repeat, that the broth be "spilt". (...) Don't the people of Lisbon deserve to be helped out of their psychic stagnation, instead of putting the radio in the service of their own stagnation? (Moita, 1936, pp. 168–171)

This is, in this case, a case of defending a cantonment of fado, the containment of the "virus" (Moita's 1936 own term), a strategy that admits some tolerance towards radio, but whose purpose would naturally be a pedagogical restriction of its broadcasts.

Beyond the "moralist" obsession of the censors[14] and beyond the differences between these two currents, what is revealed is that both saw as insufficient the political

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[12] During the First Republic, Augusto da Cost had been the main writer for the daily publication *A Monarquia*, one of the organizations of the Lusitanian Integralism movement.

[13] In 1929, and in a context where radio broadcasting was not yet in question, another individual associated with the Lusitanian Integralism movement, Silva Gaio, defended the mere preservation of some "pathological examples" of fado.

[14] Fado newspapers are also targeted in advance by the Censorship Commission, as evidenced by their editions during the 1930s.

neutralization of fado that since the beginning of the dictatorship had been done through the ideological censorship of the lyrics of the "subversive" and revolutionary line that existed before and during the First Republic (Nery, 2012, p. 231) and in which fado had been a vehicle of expression of the emerging proletariat and of denunciation of social inequalities (Brito, 1999, p. 34). What was at stake now were not politico-ideological issues that the censorship of lyrics could solve, but the cultural genre itself, in a classist repulsion that emanates from descriptions such as Moita's (1936) and that addresses fado as a symbolic form of the popular urban classes.

At that moment, however, fado was present in the entire Lisbon radio spectrum and, as we have seen, the fado hosts had already incorporated radio as a means of diffusion and propaganda, with their own series of lectures, organization of broadcasts and allegiances between the press and broadcasting stations. Thus, the great impact that Luiz Moita's lectures had in the field of fado was reflected not only in the newspapers, nor only in the small "popular" stations, but also through Emissora Nacional itself in the space of interpellation from the fado audience that were the broadcasts from Retiro da Severa.

In the May 6 broadcast, the fado singers responded to Luiz Moita's first lectures with their own weapons in broadcasted fado verses. Among them was a fado entitled "Oito Conferências" (Eight Conferences), sung by Rosa Maria, with authorship by Francisco Radamanto, which also glossed the limits of Moita's own erudite persuasion over the popular audience: "maybe it can't even/ be listened to by the people.../ Because listening to it turns you off/ and you go looking for fado!" (*Guitarra de Portugal*, 1936, p. 5).

To say that fado was implanted in radio does not mean, however, to affirm that it had reached a respectable status since its stigmatization would still be brandished for a long time in conversations against the genre, and the stigma was sometimes even incorporated by the popular classes[15].

The conquest of respectability would be a slow process, but there is no doubt that the presence of fado singers in radio stations was seen simultaneously as a factor and a sign of a road already travelled in the mid-1930s. In a balance of its 13 years of existence, *Guitarra de Portugal* traced its evolution: "women were not allowed, for reasons of decency, to sing the fado. (…) And today? the fado singers are artists, they go everywhere (…), and even TSF (Radio Station) looks for them" (*Guitarra de Portugal*, 1935, p. 2). Signs of the gradual legitimization of fado in the radio field can also be seen in *Rádio Semanal*, a supplement of *Jornal do Comércio e das Colónias* that in its editions privileges erudite culture and begins by completely ignoring fado, but that in 1936 announces Luiz Moita's lectures without echoing his positions and, on the contrary, publishes a photo of Maria do Carmo on the cover, "the well-known and appreciated singer" responsible for the broadcasts of Rádio Peninsular (*Rádio Semanal*, 1936, p. 1).

The legitimization process felt by the fado artists themselves appears increasingly linked to their broadcasting and the support of the public opinion, as expressed by the singer Alcídia Rodrigues in an interview:

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[15] Amália Rodrigues states, in the biography written by Vítor Pavão dos Santos (2005), how in 1939 she did not return to Retiro da Severa after a first rehearsal because of the opposition of her family, for whom "singing fado was doom" (pp. 53–55).

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> [question] If one day they forbid, as the detractors want, the Fado on the radio, would you agree? [Answer] That would be the death of the broadcasting stations and the National Broadcasting Station itself. From one day to the next, 90% of the radio owners would put away their devices. (*Guitarra de Portugal*, December 8, 1935, p. 2)

It is difficult, however, to have a precise idea today of the quantitative presence that fado had in radios throughout that decade. Luiz Moita, in 1936, talks about "radio stations, in Lisbon, where almost nothing else is done but successive broadcasts of fados" (p. 163), but it must be taken into account that such a description is part of a discourse intended to fight against the proclaimed excesses of fado. We know, however, that the total duration of radio broadcasts that year was only 2 hours a day in each of the small stations[16]. In the first months of 1936, only one of these radio stations had a periodic program of fados in its programming: Rádio Peninsular, which directly transmitted, on Sunday afternoons, the mentioned broadcast organized by the fado singer Maria do Carmo, in what may have been the first regular in-studio fado show[17]. The remaining stations advertised, almost exclusively, programs of "varied music", about which we can only speculate on which part was occupied by fado. We know, on the other hand, that in Emissora Nacional, the time occupied by fado transmissions throughout 1935 and 1936 never exceeded 6% of the musical sections, and that the direct broadcasts of Retiro da Severa corresponded to 40 minutes per week.

But, regardless of the periodicity and broadcasting time, it is very clear that the presence of fado in radios was consolidated in the second half of the 1930s, because, besides those already mentioned, we find later allusions to other regular broadcasts, usually organized or directed by fado singers: Rádio Graça broadcast sessions organized by António Montoia (*Coração do Sul*, August 16, 1936); Rádio Sonora had broadcasts directed by the singer Raquel de Sousa (Machado, 1937, p. 188); Margarida Pereira was in charge of the program "Fados e Guitarradas" launched by RCP in September 1937[18]; and finally Maria Teresa de Noronha inaugurated in 1938 a fortnightly program of fados from the studios of Emissora Nacional, which coexisted with the broadcasts of Retiro da Severa until 1939[19]. Thus, the radio structuring process (which in the first half of the 1930s had multiplied the fado broadcasts on an occasional basis) started, after 1935, to additionally structure the fado presence with regular programs and broadcasts in the generality of the radio spectrum.

On the reception side, it is not possible to have an accurate picture of the reality of fado listening, but there are indications that the search for the genre was effectively an

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[16] According to the programming published in *Rádio Revista*.

[17] The show was on for, at least, the first half of 1936, marking its presence in the radio programming published in *Rádio Revista*.

[18] This shows is sometimes considered as the first aired from a studio in which fado had a regular presence, but in fact it was preceded in local radio stations, at least, by the alluded Sunday program from Rádio Peninsular, led by Maria do Carmo in 1936. The premiere of the RCP show in 1937 is mentioned in the magazine *Antena* of RCP from October 1, 1965.

[19] Shows broadcast from Retiro da Severa cease to be mentioned by the end of 1939 in the Emissora's show published in *Rádio Nacional*.

ingrained practice in popular circles. A *Rádio Revista* report relates a visit to three taverns to inquire about radio preferences:

> for the tavernkeeper (all tavernkeepers, after all), if there is a transmitter station transmitting fados, he doesn't want another option (...). In a tavern, it is not possible to talk to only one person (...). All, or almost all, vote for fado (...). Most of them know the names of almost all the singers and discuss their merits heatedly. (*Rádio Revista,* January 1, 1936, p. 7)

In a series of life stories collected in Alfama, there are also memories of intensive listening to fado on the radio: "when radio started here in Portugal, we used to listen to Manuel Monteiro and Hermínia Silva all day long – we played it five hundred times"[20] (Costa & Guerreiro, 1984, p. 110). From a different class position, however, one finds an audience that reproduces criticisms analogous to those of the regime's intellectuals: "the Retiro's *desgarradas* is inadmissible on a classy radio station"[21] (*Rádio Revista*, January 1, 1936, p. 6).

Conclusion — Towards the 1940s

The 1st decade and a half of radio broadcasting in Portugal (from 1924 to 1940) represented for fado a dilemma in its history because it aggravated the cultural tensions around this popular urban genre and the unprecedented possibilities for its public legitimization that were put forward by the first social communication media not contained by the limits of illiteracy and that lent itself to a sound experience close to popular forms in its diffusion and daily practice.

It is noteworthy, however, that in a dictatorial context, fado ended up resisting an ideological offensive from notable sectors of the regime and imposed and affirmed itself in the public space. This affirmation, also made against the backdrop of bourgeois morality, which besides trying to prevent a symbolic recognition of the "culture of the poor", also fought the very fado ethos in what it presented as contrary to either the Estado Novo ideological project of vigorous regeneration of the nation or the values of merit and individual entrepreneurial initiative on which the hegemony of the bourgeoisie is based, absolutely adverse to the taste for melodrama that filled much of fado with the misadventures and misfortunes of the underprivileged classes.

The then emerging radio was the stage, at the same time, of the offensive against fado and of the fado resistance. However, this was not an ideological resistance to the regime, but a cultural one, linked to forms of popular expression, but also to dynamics of professional affirmation of an artistic medium that increasingly follows the paths of spectacle and mediatization.

The process of the consolidation of the fado artist on the radio ended up being done in three phases, roughly corresponding to:

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[20] Testimony of amateur fado singer Armando Santos.

[21] Office worker surveyed in the aforementioned Rádio Revista report, January 1 1936, p. 6.

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1. the second half of the 1920s, with an occasional inclusion of fado in radio concert programs and first sporadic broadcasts of fado sessions;

2. the early 1930s, with the emergence of studio broadcasts and widening of diffusion through records, in a conjuncture favoured by small stations close to the Lisbon popular milieus;

3. from the mid-1930s to the end of the decade, with a regular radio presence and structured fado programs in national broadcasting stations.

Not by chance, the 1920s and 1930s are the period in which the "defining leap" of fado as an autonomous genre in its musical characteristics based on a harmonic base on which the voice can "sing with good style" (Carvalho, 1994, p. 96). In other words, fado fixes the improvisational character of its performance at the level of vocal tempos and ornaments, abandoning the improvisation of the lyrics that was typical of the common *desgarradas* until the first quarter of the 20th century and that censorship now represses (Brito, 1999, pp. 34–35), which also responds to a growing context of the music industry and professional regulation, but keeps a performative dimension enough for the radio, especially with direct broadcasts, to also mediate a certain fado originality.

All this indicates that the crucial process of artistic definition that fado goes through in this stage is being done in articulation with the radio field. But, as we saw, the articulation between radio and fado didn't happen simply through musical spaces and had an important element in the discourses about fado, many of them developed on the radio and/or about radio. This extends and deepens the discussion that already came from the press, but the radio itself is now the motivation and object of symbolic struggles around fado, with the fadophile community using public opinion as a legitimizing element that is sustained on radio listening itself.

Despite the radio consolidation that fado achieved, the continued attempts to delegitimize it and to stop its expansion, both territorial and class-based, did not stop at the end of the 1930s. With the inauguration of António Ferro as director of the Emissora Nacional in 1941, a decade was dedicated by the Secretariat of National Propaganda to the simultaneous containment and toning down of fado, essentially giving institutional continuity to the critical discourse that argued for its cantonment.

The 1940s deserve their own specific analysis, but some of its traces derive from the will of the regime already evident in the previous stage, which led to a retreat of the radio presence of fado in favour of "light music" and other genres to the training of fado singers by the state radio within a "sanitized" logic of the national song, the entrance of the public itself in the heated debates about the broadcasting of fado and, lastly, the inflexion, by the end of the decade, of the official attitude towards fado after the emergence of a new internationalizing potential with Amália Rodrigues.

Translation: Susana Valdez

References

Brito, J. P. de. (1999). O fado: Etnografia na cidade. In G. Velho (Ed.), *Antropologia urbana. Cultura e sociedade no Brasil e em Portugal* (pp. 24–42). Zahar.

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"The People Turn it Off and Go Out Looking for Fado" — Radio and the Fado Resistance to the Estado Novo in the 1930s · José Ricardo Carvalheiro

Carvalho, R. (1994). *As músicas do fado*. Campo das Letras.

Costa, A. F., & Guerreiro, M. D. (1984). *O trágico e o contraste*. D. Quixote.

Fortes, J. M. (1926). *O fado — Ensaios sobre um problema etnográfico-folclórico*. Companhia Portuguesa Editora.

Machado, A. V. (1937). *Ídolos do fado*. Tipografia Gonçalves.

Moita, L. (1936). *O fado – Canção de vencidos*. Empresa do Anuário Comercial.

Moreira, P. R. (2012). *"Cantando Espalharei por Toda a Parte": Programação, produção musical e o "aportuguesamento" da "música ligeira" na Emissora Nacional de Radiodifusão (1934-1949)* [Doctoral dissertation, Universidade Nova de Lisboa]. RUN. http://hdl.handle.net/10362/9477

Nery, R. V. (2012). *Para uma história do fado*. Imprensa Nacional – Casa da Moeda.

Neves, A. (2017). *Armando Neves: Um vulto esquecido do fado*. Edições DG.

Ribeiro, N. (2005). *A emissora nacional dos primeiros anos do Estado Novo, 1933-1945*. Quimera.

Rosas, F. (2018). *A Primeira República, 1910-1926: Como venceu e porque se perdeu*. Bertrand Editora.

Santos, R. (2005). *As vozes da rádio, 1924-1939*. Caminho.

Santos, V. P. dos. (2005). *Amália – Uma biografia*. Presença.

Sucena, E. (1993). *Lisboa, o fado e os fadistas*. Mutilar.

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World Out of Place: The Degradation Trajectory of Holiday Building From the Perspective of Bourdieusian Social Space

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Abstract

This article, considering Bourdieusian sociology and its conceptual notions of social space and lifestyles, launches a reflective analysis of the biographical trajectory of symbolic degradation of an emblematic edifice built in Recife (Brazil) — the Holiday Building. Located in Boa Viagem, one of the wealthiest neighbourhoods in the city, the building is an icon representative of the arrival of modernity in the capital and marks a period of important changes in the landscape and lifestyles of Recife. With 416 small apartments that could accommodate more than 3,000 residents, this building showcased the experimental design of summer apartments for the middle and upper classes, but by the 1970s, it already showed signs of devaluation within a neighbourhood with an upward social trajectory. As defended by Bourdieu, our analytical tools use authorial photography and images of the building. Photographic materials are used to build a "before" and "after" eviction from the Holiday, using essays by two journalists from Recife as the primary guiding thread of the analysis. The results contribute to a better understanding of the symbolic dimension of housing in the urban social space. The article also suggests a turning point in discussions around the reception and the contours modernity acquired in southern hemisphere metropolis, such as Recife.

Keywords

Holiday Building, social space, life styles, ways of living, Pierre Bourdieu

O Mundo Fora do Lugar: A Trajetória de Degradação do Edifício Holiday Sob a Perspectiva do Espaço Social Bourdieusiano

Resumo

À luz de uma sociologia bourdieusiana e suas noções conceituais de espaço social e estilos de vida, este artigo lança uma interpretação reflexiva sobre a trajetória de degradação simbólica de um emblemático prédio construído em 1957 no Recife (Brasil) — o Edifício Holiday. Situado em Boa Viagem, um dos bairros mais ricos da cidade, a edificação é um ícone representativo da chegada da modernidade à capital do estado de Pernambuco e marca um período de importantes modificações na paisagem e nos estilos de vida do Recife. Com 416 pequenas habitações aptas a receber mais de 3.000 moradores, o projeto experimental de apartamentos de veraneio para classes médias e altas na década de 1970 já apresentava sinais de desvalorização em um bairro de trajetória social ascendente. Nosso instrumental analítico, tal como defendido por Bourdieu,

recorre à fotografia autoral e a imagens do edifício. Utiliza-se de materiais fotográficos para construir um "antes" e "depois" da desocupação do Holiday, tomando como principal fio condutor da análise ensaios realizados por dois jornalistas recifenses. Os resultados nos auxiliam a entender melhor a dimensão simbólica da habitação no espaço social urbano. Não obstante, o artigo oferece um ponto de inflexão nas discussões acerca da recepção e dos contornos próprios que a modernidade adquiriu em metrópoles do hemisfério sul, como é o caso da capital recifense.

Palavras-chave

Edifício Holiday, espaço social, estilos de vida, modos de morar, Pierre Bourdieu

Introduction

This article takes as an object of study the social and historical trajectory of the Holiday Building, one of the first skyscrapers in Recife (Brazil). It is emblematic in its purpose of inaugurating a culture of architectural and urban modernity, which was not achieved due to its rapid decay as an architectural gesture in a neighbourhood that, nevertheless, experienced rapid development and appreciation. In looking at such phenomenon, from a social and urban perspective, we instrumentally adopted theoretical concepts and methodological procedures of the French sociologist Pierre Bourdieu (1981/1983, 1993/1997, 1977/2001, 1980/2009, 1991/2013, 1979/2017).

The Holiday was built in 1957, and its design was signed by the engineer Joaquim de Almeida Marques Rodrigues (Docomomo_Brasil — Núcleo Pernambuco, 2016, p. 146). Despite some uncertainties about the true authorship of the project, it is clear its design was strongly influenced by the modern, international architecture, in the model of the Housing Unit of Marseille, an iconic multi-family building designed by Le Corbusier, with small units arranged in a vertical blade, making it possible to enjoy the seascape. In Recife, the Holiday has 18 floors, accommodating 416 small dwellings, with a capacity of lodging more than 3,000 residents. The building helped consolidate Boa Viagem as a residential, commercial, and service district, for until then, it had been an important summer holiday destination in the city (Figure 1 and Figure 2).

Figure 1 *Holiday Building in 1967*

Source. From Recife de Antigamente, by Jorge Moura, 2020, Facebook (https://www.facebook.com/recantigo/photos/pcb.2959346344205896/2959346230872574)

Figure 2 *Holiday Building in 2019*

Credits. Google Maps. © 2019 Google

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Idealised as the development of flats for the middle and upper classes of Recife society, such a housing proposal quickly fell into dislike. In the 1970s, the Holiday had already shown a downward social trajectory in a neighbourhood with an upward social trajectory.

In the media, during the same period, the building was often associated with homosexuality, prostitution, and drug use, and while the wealthier classes gradually stopped frequenting it, the place started being occupied by poorer people. The symbolic degradation added to its structural deterioration made the Holiday earn the nickname of "vertical slum" at a certain point in time. Finally, in March 2019, its last inhabitants were evicted. Such nuances and complexities permeating its biographical trajectory of decline, marked by progressive devaluation, degradation, and deterioration, even in such valued area of the city, are discussed here from the point of view of important Bourdieusian analytical instruments, such as the concepts of social space, *habitus*, and lifestyles (Bourdieu, 1993/1997, 1979/2017).

As Bourdieu and Bourdieu (1965/2006) argue, authorial photography can be used as a "lay sociogram". Images of the building, its surroundings, its residents, and its daily life are gathered here for a pragmatic analysis of the existing symbolic elements, which surround and overlap the "inverted world" that the Holiday represents. The exercise of interpretation of the trajectory of this building is mediated by the analysis of 21 images extracted from two photo essays made by two photojournalists from Recife. The first essay, made in 2018 by Alexandre Gondim, recorded the daily life, the surroundings, and the home's privacy of some resilient residents of the building. The second essay, made in March 2019 by Marlon Diego, recorded the last 3 days of people's eviction from the iconic building.

Among the images selected, there are those which allow an interpretative analysis of the lifestyles of the Holiday last residents. This way, certain elements extracted from the analysis allowed us to understand better the relationship of the groups portrayed with the inhabited space. Furthermore, the notion of symbolic violence (Bourdieu, 1977/2001) has been brought into the play to analyse the results and help us interpret particular dynamics of prominence and symbolic power that encompass the housing production and consumption in the city. Finally, the exercise offered a turning point for the reception, resistance, and adaptation by local elites of certain constituent symbols of modern Western culture in Recife.

The "Upside Down World": Defining the Research Problem

> A landmark. In 1957, on inauguration day, a huge red carpet adorned its main entrance. The city came to a halt. Luxury cars parked around the building. A well-born [*sic*] crowd was present. The elite was delighted with the view from the building, just a few blocks away from the beach. There were no other buildings in front. That day marked the beginning of the era of skyscrapers in Boa Viagem. It was meant to be the weekend address of

> wealthy families. Or the home of rich people's children who would come
> from the countryside to study in the capital city. In Recife of the 1960s,
> having property there was synonymous with luxury. (Quincas, as cited in
> Campelo, 2016, p. 52)

Modern design, with striking dimensions under the raw concrete, a sinuous curve of long 18 floors, where 317 units of studio flats, 65 one-bedroom flats and 34 with two bedrooms, totalling 416 units, Holiday took an entire block of Boa Viagem neighbourhood and could be seen from many miles away. Under a concept very much in vogue in the modern architectural thought of its time, the project employed the existence minimum — seeking a housing solution to enable human habitation in minimum dimensions (Ascom UFPE, 2019). An experimental and quite innovative urban development for its time, also characterised by the mixed use of space: it combined services and shops on the ground floor with flats for housing on the other floors.

One of the first skyscrapers in Recife, the Holiday impacted the city landscape for its unique shape and for being one of the first architectural examples which introduced a new way of living in the city: large-scale collective housing. An atypical housing condition for the time and the local social context, since the project initially envisaged as its target public the upper and middle classes from Recife. These classes had access to credit and an interest in having a second home and a summer house or even a profitable real estate investment. The advertisements, aimed at this specific public, highlighted the notions of "luxury", "good taste", and "comfort" that the project — as "modern" as it was "majestic" — would offer to its buyers:

> a jewel [*sic*] of modern Brazilian architecture. On the occasion of the handover of the majestic HOLIDAY BUILDING, we extend our warmest congratulations not only to its audacious developers, INVESTIMENTOS REAL LTDA but also to its happy owners and the city of Recife. To the investors for their audacious initiative, good taste, and high taste for choosing the best construction products (...) To the owners, that by supporting the enterprise had a correct foresight of the wonderful comfortable conditions that they will now enjoy. To Recife, for the authentic jewel [*sic*] of the modern Brazilian architecture - HOLIDAY BUILDING, a new "postcard" of the city. ("Uma Jóia da Moderna Arquitetura Brasileira", 1962, p. 9)

The enterprise would not sell residences but would also spread a new, "modern" lifestyle for the city: a summer house close to the sea1 (Ascom UFPE, 2019). This idea is suggested by the very name given to the enterprise, a term in English, "holiday". The aesthetic arrangements of the dwellings themselves implicitly imposed minimalism in

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1 In this sense, the expression "modern style" concerning the Holiday may be a reference to its form, but not to the purposes at the origin of the modern typology of minimal and large-scale housing. Like the Housing Unit of Marseille, with 18 floors and capacity for about 1,600 inhabitants, such an approach emerged after the Second World War as a response to the need of meeting the housing deficit of a population relocated after the bombings. In its programme, the building also suggested spaces for community life, shopping and leisure, just like a neighbourhood or a vertical city.

the furniture of the buildings and the nowadays beachy outfits of their residents, and a closer coexistence among the special and prestigious residing families, with the shared and collective use of the floors, lifts, and pavements.

Despite its foundational coastal landscape — arising from a small fishing village surrounded by a small church, embedded in coral reefs (Freyre, 2015) — Recife had its development driven by the Capibaribe Valley, the river defining the north and west growth axis of the city. The Capibaribe River defines the north and west growth vector of the city. Large and spacious country houses and townhouses of the elites of the "sugar society"[2] (Villaça, 2007) have been established on its banks. This way, until the 1960s, the upper and middle classes from Recife were hardly integrated into the landscape of salt, sun, and sea; neither were they subject to the lifestyle and housing model envisioned by the Holiday project.

As a result, the building quickly fell into the dislike of the wealthier portions of Recife society. As it ceased to be frequented by the upper class's most traditional and sophisticated families, several reports indicate that the flats were occupied by the mistresses of the city lords of power (Alves, 2019). In the 1960s, as can be seen in the *Diário de Pernambuco* archives (http://memoria.bn.br/DocReader/docmulti.aspx?bib=029033&Pesq=), mixed with the newspaper ads and buy and sell offers on its classified ads, the Holiday was already the subject of successive scandals in the police section of the newspaper, involving prostitution, corruption of minors and murders:

> although the *cause of death* is unknown, strong indications continue to point out the driver José as the probable killer of the blonde from *the south zone cabarets* [*sic*]. A witness dwelling in the Holiday informed the police commissioner that, last Friday night, he had heard cries for help coming from Maria Rita's flat. He did not pay much importance to the fact because shouts are normal in the Holiday. ("'Loura do Holiday' Teria Pedido Socorro Antes de Ser Estrangulada", 1967, p. 7)

Recurrent newspaper articles would progressively situate the Holiday as a "den of rioters, tramps, pot smokers, and other misfortunes" ("Boa Viagem", 1967, p. 3). That marked the place with a strong stigma, which continues, associating it with criminality, violence, and danger. Over time, its strong symbolic degradation once and for all drove the upper and middle classes away from its premises, and the building became increasingly inhabited by low-income populations. They were mostly informal workers and minimum wage earners of the Boa Viagem neighbourhood: informal traders, beach hawkers, maids, doormen, waiters, caretakers. For these people, the Holiday offered a unique housing opportunity.

The deteriorated and compromised structure in several building points exposed its dwellers to the risk of death. That was the reason behind the interdiction procedure

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[2] That is how Freyre (2015) described the rigid, patriarchal, slave-owning and landowning family system that made Recife one of the country's main cities over the 18th century, but which saw in the early 19th century the apogee of its economy based on the export of sugar. That was when Recife started to gradually fade to other Brazilian urban centres (Villaça, 2007).

from the Court of Justice of Pernambuco in March 2019, evicting its last residents. Notwithstanding these facts, passionate stories abound in newspapers' articles about the Holiday (Rafael Paranhos, 2013). In fact, from the pragmatic point of view and the immediate need for housing in an area of such high real estate value, the building offered an important housing solution for the neighbourhood working class: central location in the region, rents at prices below those practised around the neighbourhood and everything just a block away from the beach. Still, beyond the pragmatic point of view, one can understand that living in such a "noble" neighbourhood and overlooking the sea represents an important expression of achievement and prestige for a city working class like that one of Recife, which coastal strip has been dominated mainly by its economic elites.

Today, with the historical cycle of the building practically ended, it would be easy to say how doomed to failure this project was, so praised it was at its inauguration as "modern", "innovative", and "majestic". The Holiday project is based on an ideal of modernity associated more with formal aesthetics (of the physical space) than with programmatic issues (of the social space); it was developed around an architectural typology that proposed a form of communal living that was all but contradictory regarding the public's lifestyles to which it was initially intended. The large-scale multi-family housing model did not meet the demands of the local elite for "satisfaction and comfort". Displaced in time and space, even today, the Holiday is an "inverted world", in a constant relationship of "opposition" and "complementarity" with its outside world (Bourdieu, 1980/2009, p. 437), surrounded as it is by high-standard buildings. It builds a relationship of opposition because, standing at the heart of Boa Viagem, the Holiday appears, to the local elite's eyes, as a "vertical slum", inconveniently occupying the landscape and the social world of that noble neighbourhood. It also builds a complementary relationship with the exterior through its diverse and resilient popular uses and appropriations of the building and its surroundings for leisure, sociability, and work.

In many contemporary cities, in some more than others, we still see a dynamic in the real estate market of housing sales that employs advertising strategies associating the building to a certain "lifestyle", that is, with a specific and distinctive way of living and experiencing the city. This way, instead of constituting a unique property for life, the building requires at least modifications after a certain time, or even its replacement because it no longer represents what is most modern and sophisticated in the market (Ascom UFPE, 2019). The Holiday Building seems to be a relevant example among a set of enterprises that arrived in Recife, which brought new dynamics to the phenomena of development and production of the city. Still, it went through a historical time of several accelerated changes, but mainly of local resistances and adaptations, facing the modernisation trends of the city lifestyles.

Nevertheless, faced with the public challenge of understanding the "Holiday Building" phenomenon and its biographical trajectory, we turn to sociology, where the Bourdieusian perspective offers a particular and fascinating viewpoint on social relations among classes and the mechanisms of symbolic prestige that lends meaning and strength to the dynamics of housing and cities development and production.

Theoretical-Analytical Proposal: The Bourdieusian Social Space and Housing as a Lifestyle

As already stated, our analysis has its theoretical-analytical proposal based on the thought of Pierre Bourdieu (1930–2002). With an undisputed biography, the body of work of this thinker covers a wide area of knowledge, finding resonances in different fields of social and humanistic knowledge (Peters, 2018). In a specific way, the Bourdieusian project successfully built a theoretical and methodological framework for investigating cultural and symbolic mechanisms of domination and power in Western societies of his time.

In this article, our analysis is precisely an attempt to apply some of this author's concepts to interpret social fabrics presented and engendered in the city, especially regarding the symbolic systems of distinction and power around housing. As a first step, it is necessary to understand Bourdieu's theoretical perspective on social space (Bourdieu, 1979/2017, p. 116), where its multidimensionality is structured in three dimensions. The first one, *the space of social conditions*, accounts for the social positions that each individual occupies in society (class, family origin, gender, race, etc.). On the other hand, *the space of lifestyles* seeks to unveil the set of individual practices and properties, which each individual has accumulated in the course of his trajectory, despite his pre-existing social conditions (professions, material goods, friendships, leisure, aesthetic taste). Between these two dimensions presented, *the theoretical space of habitus* brings another theoretical notion of the author, developed to explain the generative formulas of practices and properties, that is, of the transformations of distinctive and distinctive lifestyles that each agent has adapted from his social condition and position in society (Bourdieu, 1979/2017, p. 162). According to the author, the social space, apprehended from its multidimensionality,

> allows, in fact, to realise that the rate of conversion of the different species of capital is one of the fundamental pretexts of the struggles between the different fractions of the class which power and privileges are related to one or another of these species and, in particular, of the struggle over the dominant principle of domination - economic capital, cultural capital or social capital. (Bourdieu, 1979/2017, p. 115)

In short, social space is a Bourdieusian analogy for society and a sociological reading of its system of social positions — the place each agent occupies in society in relation to others. Bourdieu (1991/2013) also perceives the dual dimension of the human being as a physical-biological body and a social agent — while the individual is situated in a social "place", he also occupies a physical "place". The author (Bourdieu, 1991/2013, p. 134), who differentiates the place from the local, tells us that "place" is defined as the *location* of an individual in social space and a *position* that the agent occupies within a social order. The "place", on the other hand, means the physical volume, that is, the material dimensions that a body occupies or has dominance in the physical space, such as private property, vehicles, flats, offices, companies, summer houses.

In effect, social space tends to reproduce itself more or less rigorous in physical space, under the form of a certain distributive arrangement of agents and their properties.

Thus, the coexistence of agents and properties is translated into the *appropriated physical space* — or, what would be the same, the *reified social space*. "Consequently, the place and location occupied by an agent in the appropriate physical space constitute excellent indicators of his position in the social space" (Bourdieu, 1993/1997, p. 134). It thus becomes possible to understand the links that the social space nurtures with the physical space: the former is "retranslated" into the latter. In its turn, the effects of place (Bourdieu, 1993/1997, p. 160) in the social life of the agents are the possibilities of access to the various types of economic, social, cultural, and symbolic capital:

> the power over space that the possession of capital provides, under its different kinds, manifests itself in the appropriate physical space in the form of a certain relationship between the spatial structure of the distribution of agents and the spatial structure of the distribution of goods or services, private or public. (Bourdieu, 1993/1997, p. 160)

At the same time, the accumulation of capital by agents favours their domination of the appropriated physical space — which often manifests itself in the form of distinction and distance, whether physical or symbolic, from unwanted things and people. The dominant classes — possessors of large volumes of capital — possess the power to appropriate places even at a distance, while the *destitute* do not possess the same power of appropriation over the same places. While capital endows its holders with mobility over space, the destitute are subject to certain immobility in space, occupying places situated as sites of social dishonour. The effects of place reinforced the positions of dominator and dominated in space. According to Bourdieu (1991/2013), appropriated space is understood as:

> one of the places where power is asserted and exercised, and probably in the most subtle form, that of symbolic violence as unnoticed violence: the architectural spaces - whose silent injunctions address the body directly, obtaining from it, as surely as the etiquette of the court societies [*sic*], the reverence, the respect that, as the Latin says, is born from distancing (e longinquo reverentia); or rather, from being far away, the respectful distance - are undoubtedly the most important components of the symbology of power, by reason even of their invisibility. (p. 135)

Through this interpretative path, the dwelling itself is constituted of a unitary set of properties that reveals the lifestyle of its inhabitant, a "symbolic retranslation of differences objectively inscribed in the conditions of existence" of the social space (Bourdieu, 1981/1983, p. 82). As it is understood from its location on the map, neighbourhood, design, furniture, and even the type of material employed in its construction, each housing unit becomes an important operator of distinction of its inhabitant in the social, urban world. The symbolic power of housing is to reveal the social position of its inhabitant within a social order, objectified in the city's physical space. This symbolism confers to the subject a series of specific statuses, which are socially attributed to them. An example

of that is the air of nobility and consecration attributed to the dweller of Apipucos, an upper-class neighbourhood in the north zone of Recife. Or, in its opposed direction, the stigma of criminality and degradation falls on a dweller of Coque, a low-income neighbourhood located in the city's central region.

Therefore, housing as a lifestyle is inscribed simultaneously in the spatial structures' objectivity and in the subjective structures of the agents who are, to some extent, a product of the incorporation of these objectified structures. Moreover, the prolonged stay of an agent in a given place leads to the formation and accumulation of different and specific capitals specific to that place. The habitat contributes to the constitution of the *habitus*, just as the *habitus* contributes to the constitution of the habitat (Bourdieu, 1993/1997). The *habitus*, this symbolic operator that guides people's actions and is the product of the relationship among themselves, promotes the perception of each individual and is socially appropriated and improved:

> a structuring structure that organises practices and the perception of practices, the *habitus* is also a structured structure: the principle of division into logical classes that organises the perception of the social world is, in turn, the product of the incorporation of the division into social classes. Each condition is defined, inseparably, by its intrinsic properties and by the relational properties inherent to its position in the system of conditions, which is also a *system of differences*, of differential positions, that is, by all that distinguishes it from all that it is not and, in particular, from all that is opposed to it: social identity is defined and affirmed in difference. (Bourdieu, 1979/2017, p. 164)

The potential generator of *habitus* is perceived as an invisible, tacit, essentialised and naturalised element in human actions, consisting of inherent dynamics that imperceptibly engender social practices. It is considered invisible, except for the evidence of strategies in producing and reproducing objective and material structures. After all, the strategies — and lifestyles — give materiality to the practices as products.

Particularly important in the ontology of this author's thought, the notions of *habitus* and lifestyles occupy an important place in his analytical scheme on the structures of social positions of agents in space. The ways of living in the city, where different and distinctive lifestyles are outlined, can be understood in the light of Bourdieusian thought as important categories of analysis of the mechanisms of distinction that govern the relationships between the dominant and the dominated in a given urban society. Engendered in such a way in the social fabric of the space, the ways of living have the potential not only to distinguish and classify their inhabitants but are also important symbols of desire and taste among city dwellers:

> the taste, propensity, and aptitude for appropriation - material and/or symbolic - of a certain class of objects or classified and classifying practices is the generating formula at the origin of *lifestyle*, a unitary set of distinctive

> preferences that express, in the specific logic of each of the symbolic sub-
> spaces - furniture, clothing, language or corporal *hexis* - the same expressive
> intention. (Bourdieu, 1979/2017, p. 165)

We see that an individual's position in the city map may say a lot about the social position they occupy in society. However, the interior of their own house may also show paths, choices, and deviations that they took during their trajectory — in their symbolic struggle for repositioning in the social sphere. The subtleties of the internal environment of a house may well symbolically inform about the "good taste" or the "vulgarity" of its owner, as well as the amount of economic capital he had or did not have to invest in his dwelling. That is so because the material, concrete structures, inseparably ethical and aesthetic, are the centre and front of an agent's home. They not only categorise their practices, tastes, and lifestyles, but they also inform us of which symbolic fields and systems this agent is linked to:

> symbolic power, as the power to constitute the given through enunciation, to
> make one see and make one believe, to confirm or transform the vision of the
> world and thus the section on the world, thus the world; quasi-magical power
> that allows one to obtain the equivalent of what is obtained by force (physical
> or economic), thanks to the specific effect of mobilisation, is only exercised if
> it is recognised, that is, ignored as arbitrary. This means that symbolic power
> resides in "symbolic systems" in the form of an "illocutionary force" but that
> it is defined in and through a determined relation between those who exercise
> power and those who are subject to it, that is, in the very structure of the field
> in which belief is produced and reproduced. (Bourdieu, 1977/2001, p. 15)

In possession of these considerations about the social space in the thought of Bourdieu, we see that symbolic systems — products and producers of our lifestyles — hold an inseparable relationship with the systems of power, functioning socially and politically as "instruments of imposition or legitimation of domination, which contribute to ensuring the domination of one class over another (symbolic violence)" (Bourdieu, 1977/2001, p. 11). Finally, we also refer to the construction of the concept of "symbolic violence", the means of exercising symbolic power, which is founded on the continuous manufacture of beliefs in the process of socialisation, which induces the agent to position himself in the social space following criteria and standards of the dominant class. Thus, symbolic violence is often manifested through the recognition and legitimacy of the "good taste" of the dominant class, followed by the copious desire for its lifestyle.

Methodological Scheme: The Photograph as a Sociogram

"And then I decided to look into a collection of photographs that belonged to Jeannot, a childhood friend: I examined them one by one and immersed myself in them. I seem to have found a lot in that shoebox" (Bourdieu & Bourdieu, 1965/2006, p. 31).

In 1965, Pierre Bourdieu and Marie-Claire Bourdieu published an article entitled "Le Paysan et la Photographie" (Bourdieu & Bourdieu, 1965/2006). That article analyses

photography's social uses and meanings in a peasant village in the French countryside, where Pierre Bourdieu lived as a kid. Beyond conclusions about the rites and celebrations of passage in a French peasant society of the mid-20th century, the article in question argued for strategic methodological use of photography in social research. Above "their technical or aesthetic qualities", photographs should be perceived as veritable "lay sociograms that make possible a visual record of existing social relations and roles" (Bourdieu & Bourdieu, 1965/2006, p. 31).

"The photograph should only enable a representation that is sufficiently believable and precise to allow recognition. It is methodically inspected and observed, from a distance, according to the logic that governs the knowledge of others in everyday life" (Bourdieu & Bourdieu, 1965/2006, p. 34).

At that time, Bourdieu and Bourdieu (1965/2006) would consider photographs of peasant weddings as true "lay sociograms" since the visual record of a moment of solemnity such as this fulfilled not only an important social role of legitimation of the ritual but also registered — in its details and in an unconscious way — the symbols and the socially accepted and regulated behaviours within a specific social order. For the analytical exercise in the present article, we seek, in a different photographed "subject", the symbols of prestige, consecration or social degradation. As the object of analysis, we took two photographic essays of two photojournalists of the city, who covered different moments of the Holiday. The first of these essays, made by Alexandre Gondim for the newspaper *El País* in 2018[3], recorded the surroundings, the daily life of the building and its residents, including the intimacy of their homes. The second one, made by Marlon Diego in March 2019[4] — entitled "Inventory" — recorded the last days of the eviction from the Holiday and the eviction action performed by the city government, revealing empty flats, silent corridors, paintings, and photographs still hanging on the walls, along with some belongings left behind.

In all, we have gathered 21 images — 10 of Alexandre and 11 of Marlon — interspersed and reorganised according to the research subjects of interest: the *building*, its façade, surroundings and daily life; the *inhabitants*; and the *dwellings*, personal objects and aesthetic arrangements of the dwellings. The analysis was carried out by a pragmatic interpretation of what was possible to extract from the photographs, the traces and cultural codes that symbolically inform the elements of distinction and variation of social classes.

We have seen that the Bourdieusian project of studying domination and power in the Western world brought the weight of the analysis to the cultural dimension, from where it is possible to see the functioning of mechanisms of distinction present in the social order, at the same time revealing the arbitrariness of what is socially legitimated as "good taste". However, the project highlights the dynamics of symbolic violence in society through the subjection of agents and classes lacking cultural capital — designated by the dominant culture as subcultures. This analytical tool also allows us to observe, in the codes and

[3] Available at https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html

[4] Available at *Trama* magazine (2019, March). This is a journalism students' magazine from the Federal University of Pernambuco. The material was cordially provided via personal request.

traces present in the images, symbols that inform of certain paths and deviations in the trajectory of the agents, in their tortuous paths of struggle and achievement in social recognition of their prestige, success, or, in the author's terms, "social position".

Results and Discussion

If looking closely, it is possible to understand the grandeur of one of the most iconic buildings in Recife (Figure 3 and Figure 4).

Figure 3 *Holiday Building facade*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Figure 4 *Holiday Building stairs*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Its shape, with its own characteristics, occupying an entire block diagonally, its multiple side accesses, its expressive sinuosity, in 18 floors with almost countless windows, the Holiday Building dominates the landscape of the surrounding waterfront, in a section of Boa Viagem, having become an important landmark. As if its aesthetic properties were not enough to make it stand out from the other high-standard residential buildings in the neighbourhood (Figure 5), the social uses of the Holiday — associated with classes of low social prestige and economic power — place it in an inconvenient position in the social space of the neighbourhood.
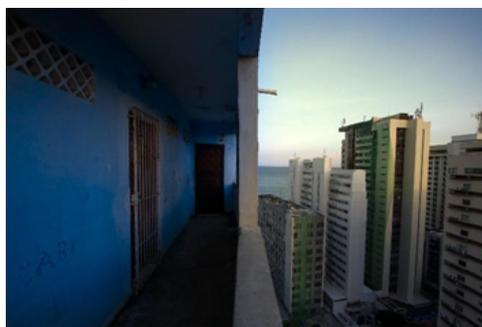
Figure 5 *Holiday Building neighborhood*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

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Wagons parked on the ground floor of the building, next to an accumulation of debris that suggests abandonment, belong to beach hawkers who live in the Holiday or use it as a supporting point (Figure 6).

Figure 6 *The ground floor of the building*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpaís.com/brasil/2017/12/31/politica/1514729934_109046. html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

The ground floor shops of the building, characterised by the supply and demand of low-cost products and services (Figure 7, Figure 8 and Figure 9), constitute a place of circulation and exchange of economic and social capital in a space appropriated by agents of popular lifestyles.

Figure 7 *Man walks in front of the stores that are in the building*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpaís.com/brasil/2017/12/31/ politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Figure 8 *S. F., 56 years old, merchant on Holiday and former resident of the building*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpaís.com/brasil/2017/12/31/ politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Figure 9 *Morador atravessa o portão de entrada do Holiday*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpaís.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

In the entrance hall of the building, among the endless advertisements for rent and sale, one can read offers of various goods and services, among them: manicure-pedicure, sale of "dudu-geladinho" (a type of frozen juice), homemade lunch, maintenance and repair of cookers, plumbing, among others, indicating not only the professional types associated with an informal working class but also an intense local dynamic of supply and demand of goods and services (Figure 10).

The Holiday residents appear to share a look of weariness and hope. Brown skins, ageing adults, and a distressing uncertainty about the future of the investment of money, time and lifestyle called Holiday. The men, portrayed on an ordinary day, are dressed less casually — shoes, long trousers, striped polo shirt, suggesting that they are engaged in work activities outside the microcosm of the large building (Figure 11).

Figure 10 *Wall with notices on Holiday*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Figure 11 *P.D., 63 years old, after 35 years working as a janitor of buildings, bought an apartment on holiday*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

One of the residents, while taking the photojournalist for a walk in the building, shows him the precarious engine room of the only lift in operation (Figure 12 and Figure 13).

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Figure 12 *The Holiday Building's elevator*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Figure 13 *The elevator engine room*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Structural improvements in the Holiday, throughout its recent history, always came up against the lack of resources of its own residents, in addition to the difficult mission of collective management of a dwelling with so many tenants[5].

The women portrayed, dressed in more casual clothes — simple beach clothes —, let themselves be photographed in their flats — perhaps the place that holds their greatest symbols of distinction and prestige. The first woman, appearing to be in her 60s (Figure 14), is recorded unveiling a partition between the kitchen of her house and a second room, proudly showing the duplex refrigerator and the double curtain with false lace.

The second woman (Figure 15), in the same age group, wearing beach clothes, hat, and glasses, is photographed sitting on her bed, under a body *hyexis* that resembles a "madam" pose and in opposition to the balcony window, where it is possible to see the beach and the sea.

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[5] This, by the way, is an essential issue for the effectiveness of social housing projects and management in Brazil, and the reason why they rarely assume a vertical position: the maintenance of common areas cannot depend on resources obtained in the form of apportionment or condominiums. Thus, these areas are incorporated into the private space of the housing units, reducing circulation space to the minimum possible.

Figure 14 *M.B. has lived for 19 years on Holiday*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

Figure 15 *M. A., 55 years old, sells hot dogs on Boa Viagem beach*

Source. From "Em Bairro Luxuoso do Recife, Edifício Mais Icônico É o Refúgio da Classe Trabalhadora" (*El País Brasil*), by Felipe Betim, 2018 (https://brasil.elpais.com/brasil/2017/12/31/politica/1514729934_109046.html). Copyright 2017 by Alexandre Gondim.R eprinted with permission of Alexandre Gondim.

A detail in the image, the faded painting on the wall that frames a panoramic view of the Boa Viagem neighbourhood, undoubtedly synthesises well the complex theoretical problem that surrounds the Holiday: the properties of its real estate — location and privileged view — are not enough for its residents to obtain symbolic recognition and a repositioning in the social space. While a beautiful panoramic view of the sea may be offered by its holder as a symbol of prestige and symbolic power, other elements that may be composing the same frame — such as the agent's body *héxis* or even the faded wall of his property — may very well reveal exactly the opposite of its dweller's interest. The conquest of a dwelling, such as the Holiday, can be interpreted, in parts, as the symbolic struggle of an agent — in acquiring property and adapting his lifestyle —, endowed with strategies to gain prestige, recognition or position in the social space. Bourdieu (1979/2017) reminds us:

> the struggles for the appropriation of economic or cultural goods are, inseparably, symbolic struggles for the appropriation of these *distinctive signs*, such as the classified and classifying goods or practices (…). Consequently, the space of lifestyles, that is, the universe of properties through which the occupants of different positions in the social space are differentiated, with or without the intention of distinction, is itself nothing more than a balance, at a given moment, of symbolic struggles which pretext is the imposition of the legitimate lifestyle and which find an exemplary accomplishment in the struggles for the monopoly of the emblems of "class", that is, luxury goods, goods of legitimate culture or the legitimate mode of appropriation of these goods. (p. 233)

The precarious structural conditions of the Holiday, to which its residents are subjected — ranging from overloaded electrical installations, leaks, infiltrations, lifts unfit for use —, may be perceived as part of the *symbolic violence*. These inconveniences are accepted and naturalised as part of a process, like rules of a game or paths of a social

space the agent needs to travel to conquer its position in the social order. However, in March 2019, the advanced structural deterioration of the building obliged the Court of Justice of Pernambuco to request its immediate interdiction. Within days, the more than 3,000 residents left the flats. Unable to remove part of their personal belongings, many residents left them behind. However, the eviction order demanded the removal of even the residents' personal belongings, and, in the same month, city hall agents went to do the "cleaning" (Figure 16 and Figure 17).

Figure 16 *Locksmith opening the door of one of the apartments*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Figure 17 *Holiday vacancy*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Interpreted as cultural codes, the objects left behind and captured by the photographs help us understand their owners' *habitus*. As an "embodied need, converted into a disposition generating sensible practices and perceptions capable of providing meaning to the practices engendered in this way" (Bourdieu, 1979/2017, p. 163), the *habitus* is the structuring structure of the daily life of the Holiday inhabitants, while it is also structured, ratified, and adapted through their daily practices. Highlight the strong presence of the Christian matrix's religiosity that permeates the agents' daily lives, manifested in the centre and details of the images (Figure 18, Figure 19, Figure 20 and Figure 21). Such as the name "Jesus" stuck at the entrance door of one of the properties; the scapular wrapped around an old picture frame with a photo of a man and a woman embracing; Our Lady of Fátima framed and fixed to the wall, next to a calendar, courtesy of a grocery store; the picture of Our Lady of Conception, left behind next to an old electrical extension cord.

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Figure 18 *Door of one of the apartments*

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Figure 19 *Belongings left in the apartment*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.
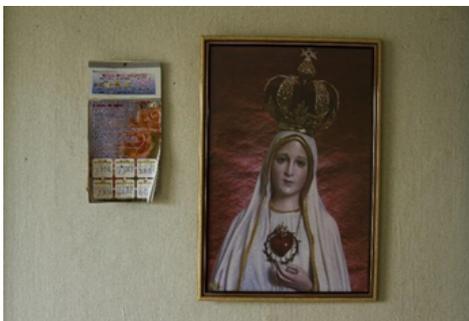
Figure 20 *Pictures on the wall of one of the apartments*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.
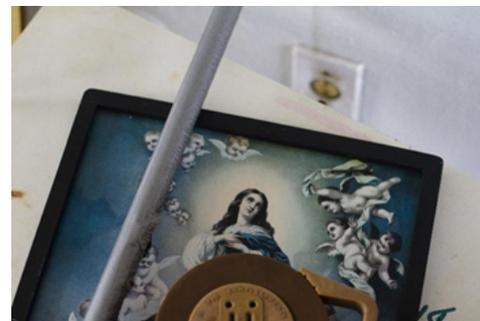
Figure 21 *Objects left in the apartment*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Coming from the social practices of creation, identification, recognition or consumption, the objects, when sociologically decoded, point to interpretative possibilities about the distinct lifestyles and individual trajectories that occupied the Holiday. A shelf full of personal objects suggests that they belonged to an older person with health care needs (electronic heart-pressure monitor), a habit of drinking tea and an appreciation for distant travels, the coconut tree portrait holder reveals a trip to a place with a milder climate — possibly made with a spouse, due to the rings and scapular, left next to the portrait. Such cultural traces profile a person with a slightly more distinctive lifestyle than the other Holiday dwellers.

The disposition of objects on the walls suggests a *habitus* and lifestyle displaced from the social space of the dominant class and its legitimated games of conduct and aesthetic disposition. The cardboard calendar, courtesy of a popular market, nailed to the wall next to the image — which is not a painting but a reproduction — of a saint and the faded wall, painted in a strong wine-red tone, with an empty cage hanging (Figure 22), point to a perception of comfort and aesthetic sense about what is beautiful or useful that departs from the legitimated "good taste" of the dominant culture.

Still, a collage on the wall (Figure 23), made with newspaper and magazine clippings, gathering phrases, texts, and images of movies and international celebrities, suggest that its creator, of a young profile, was quite identified with the pop culture, music and American cinema, symbols of a modern and globalised lifestyle.

Figure 22 *Cage in a red painted wall in one of the apartments*

Source. From "Inventário" (*Revista Trama*), by Marlon Diego, 2019 (https://tramabodoque.com/2020/08/23/inventario/). Copyright 2019 by Marlon Diego. Reprinted with permission of Marlon Diego.

Figure 23 *Wall collage in one of the apartments*

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We see from the images that a resident of the Holiday no longer holds the same efficacy of distinction, comparable to the moment of its inauguration. In its formal aspect, the modern aesthetic provisions of the development, pretentiously associated with good taste, high standards and quality of life, quickly lost their legitimacy and recognition among the dominant classes of Recife. The lifestyle that the project sought to disseminate, associated with a minimum housing model and a more collective way of living, did not confer on the first residents the desired sense of distinction and selectivity. Without recognising refinement and validation before the local elite, whose taste was still very much linked to an "aristocratic" and "sugar" *habitus*, the Holiday saw its trajectory take place through an intense symbolic degradation.

Marked by a transfer of its social use, while it no longer served a privileged economic class, the building was being occupied by popular and workers of Boa Viagem neighbourhood — changing the social position of the agents within the same physical space. Despite the advanced deterioration of its physical structure, which even put its frequenters at great risk, the Holiday never ceased to be held in high esteem by its residents. From the point of view of low-cost housing and democratisation of access to the city, the building spontaneously became an interesting housing solution for the neighbourhood working class. However, the effectiveness of Holiday as a place of popular housing near the Boa Viagem beach faces several barriers, especially in the symbolic domain, which concerns the subtle mechanisms of distinction and power over space through culture.

Final Considerations

The visit to these two photographic essays was an exercise in thinking through images about certain dynamics at the heart of access to and achievement of housing in cities.

The imagetic points of observation offered in each frame not only reveal interpretative possibilities about the contours of the trajectory of the Holiday but also shed light on the challenges of a modern urban lifestyle — of collective, large-scale housing — which began in Recife in the mid-1950s and has, in the building, one of its best examples. To this end, we present an analytical perspective through the lens of Bourdieusian sociology, where the symbolic dimension of housing explains part of the social fabrics in the city of Recife.

We resorted to some theoretical instruments of the French sociologist to explain the effects of place on the social life of the agents, and we saw that places of residence could both consecrate and symbolically degrade its inhabitant. However, the dimension of the *habitus*, which functions as a symbolic operator — materialising the life experiences of the past and the present in practices, perception schemes and strategic actions — helps us to understand the modelling of the agents' life trajectories, always in search of a relative position in the *appropriate social space*. The *habitus's* materiality is revealed through its agents' lifestyles; their dwellings, from their location, furniture, appliances, and aesthetic arrangements of personal objects, constitute important aesthetic properties and symbols of distinction and belonging to a specific class fraction and lifestyle within a social order.

These Bourdieusian analytical tools proved relevant to understanding certain cultural and symbolic dynamics related to the conquest or consumption of urban lifestyles and ways of living in the city. In turn, the analysed perspective shows us that the physical approximation between agents of distinct socioeconomic classes is not, by itself, something sufficient for effective social integration in the city. Even so, enabling the Holiday for popular and quality housing could constitute an important solution for the site. The population density of the 416 flats and its more than 3,000 residents make it a place of relative social, symbolic, and economic autonomy of popular order, in a coastal strip practically all occupied by economic elites.

It is also considered that despite the recognition as historical and architectural heritage and a certain idyllic valuation by the artistic class of the city — served, even, as a stage of Pernambuco movies and object of photographic essays —, Holiday never managed to convert its singular volume of capital in structural improvements. Recovery projects for the building face several problems, from the institutional arrangements for its financing to the necessary socio-political articulations. Finally, we endorse that the problematic of the Holiday Building is not exhausted with this work. On the contrary, we hope to have ratified the complexity present in the fabrics of the urban social space, which is a challenge to interdisciplinary studies.

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Acknowledgements

References

Alves, P. (2019, March 21). *Da inovação à degradação: Holiday representa marco arquitetônico e social para o Recife*. Globo. https://g1.globo.com/pe/pernambuco/noticia/2019/03/21/da-inovacao-a-degradacao-holiday-representa-marco-arquitetonico-e-social-para-o-recife.ghtml

Ascom UFPE. (2019, March 22). *A importância arquitetônica e histórica do Edf. Holiday* [Video]. YouTube. https://www.youtube.com/watch?v=ALeMSKjmNFY

Boa Viagem. (1967, September 24). *Diaro do Pernambuco*, p. 3.

Bourdieu, P. (Ed.). (1983). *Questões de sociologia* (J. Vaitsman, Trans.). Marco Zero. (Original work published 1981)

Bourdieu, P. (1997). *A miséria do mundo* (M. S. S. de Azevedo, J. A. Clasen, S. H. de F. Guimarães, M. A. Penchel, G. J. de F. Teixeira, & J. V. Vargas, Trans.). Vozes. (Original work published 1993)

Bourdieu, P. (2001). *O poder simbólico* (F. Tomaz, Trans.). Bertrand Brasil. (Original work published 1977)

Bourdieu, P. (Ed.). (2009). *O senso prático* (M. Ferreira, Trans.). Vozes. (Original work published 1980)

Bourdieu, P. (2013). Espaço físico, espaço social e espaço físico apropriado (A. C. A. Nasser, Trans.). *Revista de Estudos Avançados*, *27*(79), 133–144. https://www.revistas.usp.br/eav/article/view/68707

Bourdieu, P. (2017). *A distinção*: *Crítica social do julgamento* (D. Kern & G. J. F Teixeira, Trans.). Editora Zouk. (Original work published 1979)

Bourdieu, P., & Bourdieu, M.-C. (2006). O camponês e a fotografia (H. Pinto & J. Madureira, Trans.). *Revista Sociologia Política*, (26), 31–39. https://doi.org/10.1590/S0104-44782006000100004 (Original work published 1965)

Campelo, P. (2016). *Lampião da esquina*: *Descortinando o cotidiano gay entre os anos de 1978 e 1981* [Undergraduate thesis, Universidade Federal de Campina Grande]. Sistemoteca. http://dspace.sti.ufcg.edu.br:8080/jspui/handle/riufcg/5091

Docomomo_Brasil — Núcleo Pernambuco. (2016). *momo_tur_rec: Guia da arquitetura moderna no Recife*. Edição dos autores.

Freyre, G. (2015). *Sobrados e mucambos*. Global Editora.

'Loura do Holiday' teria pedido socorro antes de ser estrangulada. (1967, September 20). *Diario de Pernambuco*, p. 7.

Peters, G. (2018). Pierre Bourdieu. In S. Luçan & S. S. Telles (Eds.), *Os sociólogos* (pp. 188–215). Vozes.

Rafael Paranhos. (2013, November 26). *Contraste Vertical - (Holiday, do luxo a vida real) - Curta Nassau 2013.2 – VENCEDOR* [Video]. YouTube. https://www.youtube.com/watch?v=CRMM98EdeuA

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Uma jóia da moderna arquitetura brasileira. (1962). *Diario de Pernambuco*, p. 9.

Villaça, F. (2007). *O espaço intra-urbano*. Editora Nobel.

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Vaccination Against Covid-19 — An Analysis of Portuguese Official Sources' Digital Health Communication

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Abstract

The covid-19 pandemic poses complex challenges to governments and health authorities all around the globe. Institutions have to cope simultaneously with the efforts to control the dissemination of the disease and the need to undertake articulated health communication procedures. This communication process is challenging to manage, due to the considerable uncertainty of the available information, the increase in misinformation stemming from a scattered (and often unmediated) mediascape, and some social groups' resistance to adhere to the recommended preventive measures. Vaccination emerges as a topic that fuels extreme positions — on the one side, the eagerness for vaccine availability (which encourages illicit attempts to get it); on the other, the obstinate refusal of vaccination (based on theories with no medical-scientific grounds). In this context, we aim to assess how the leading Portuguese governmental and health institutions communicate with their audiences in the digital environment through their official websites and online social networks. In five websites and four online social networks used by the chosen sources, we have collected the content about vaccination published between the announcement of the authorisation of the first vaccine and the beginning of the administration of the second round to health professionals. Then we have applied content analysis methodology to the corpus of this case study. The results have shown that the primary Portuguese official sources give themselves the floor regarding the covid-19 vaccination process, addressing three main themes using an eminently informative frame: vaccine administration, priority groups definition and a general approach to the vaccine. Bearing in mind health communication's primary goals — engage, empower and influence citizens — we conclude that Portuguese official sources have promoted conservative forms of communication, potentially missing the opportunity to foster a more pedagogical and customised digital communication.

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Vacinação Contra a Covid-19 — Uma Análise da Comunicação de Saúde das Fontes Oficiais Portuguesas em Ambiente Digital

Resumo

A pandemia por covid-19 tem colocado complexos desafios às instituições governamentais e de saúde em todo o mundo. Para além da dificuldade em controlar a disseminação da infeção, as instituições têm de encetar um processo de comunicação de saúde particularmente difícil de gerir, por causa do elevado grau de incerteza associado à informação de que dispõem, do aumento da desinformação resultante de um ambiente mediático pulverizado (e, muitas vezes, sem mediador) e da resistência de alguns grupos da sociedade em aderir às medidas preventivas recomendadas. A vacinação surge, pois, como um tema que alimenta posições extremas — desde a ânsia pela sua disponibilidade (que potencia tentativas ilícitas de obtenção da vacina) até à sua recusa intransigente (baseada em teorias sem fundamentação médico-científica). Neste enquadramento, pretendemos avaliar a forma como as fontes oficiais — as principais instituições governamentais e de saúde portuguesas — comunicam com os seus públicos em ambiente digital, nomeadamente através dos websites e das redes sociais online. Para isso, foram recolhidos os conteúdos sobre vacinação publicados em cinco sites e quatro páginas nas redes utilizadas pelas fontes analisadas, no período compreendido entre o anúncio da autorização da primeira vacina e o arranque da administração da segunda dose aos profissionais de saúde. O material em estudo foi examinado através de técnicas de análise de conteúdo. Os resultados revelaram que as principais fontes oficiais portuguesas chamam a si o protagonismo em torno da vacinação contra a covid-19, que declinam em três temas fundamentais — administração, definição de grupos prioritários e abordagens genéricas, através de conteúdos com um enquadramento maioritariamente informativo. Atendendo a que a comunicação de saúde tem como objetivos envolver, capacitar e influenciar os indivíduos, concluímos que as fontes oficiais promoveram formas de comunicação conservadoras, perdendo potencialmente a oportunidade de fomentar uma comunicação em ambiente digital mais pedagógica e personalizada.

Introduction

At the end of 2020, after the world had suffered an *annus horribilis* due to the covid-19 pandemic, which in December totalled nearly 2,000,000 deaths worldwide (Center for Systems Science and Engineering, 2021), finally hope is reborn. Months after an unprecedented investment in medical-scientific research to find a solution that could stop the spread of SARS-Cov-2, the first vaccine against covid-19 is authorized.

In Europe, the European Medicines Agency gave the "green light" on December 21, 2021. That led to the European Commission's swiftness in authorizing the marketing

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and distribution of the vaccines in all 27 member states. The President of the European Commission, Ursula von der Leyen, announced that the vaccination process would be concerted, starting between December 27 and 29, 2020, in all 27 countries. For a while, the media and social narrative changed. The vaccine — product of the medical-scientific capacity of the old continent — and European coordination brought hope, a word much repeated in the following days.

Also, in Portugal, a country afflicted by the excessive mortality linked to the pandemic and the ageing population (around 115,000 deaths in 2020, a number unheard since 1949; Guedes, 2020), the vaccine received the most media and social attention. The official sources (associated with governmental and health institutions) involved in the complex vaccination campaign, whose imminent process carefully prepared the scenarios and strategically conveyed their messages to journalists eager for information and a society thirsty for good news on health.

However, although undeniably relevant, traditional media are not the only communication channel used by institutional sources to communicate with different groups in society. In the current "disintermediated" media panorama (Eldridge et al., 2019; Lévy, 1998), digital communication, namely through websites and online social networks, assumes a strong relevance that should be analyzed. What health communication did official sources promote there?

Theoretical Framework

Health Communication

Health communication is still a recent discipline, which has evolved at different paces in different regions of the globe and has received the most attention in the United States of America. However, even if it is still a "pre-paradigmatic" area (Araújo, 2017), its relevance is unquestionable (Ishikawa & Kiuchi, 2010) and has been reinforced with the advancement of the global pandemic by covid-19 (Fielding, 2020; Finset et al., 2020).

Health communication is a crucial strategy for informing the public about health concerns and keeping essential health issues on the public agenda (World Health Organization, 1998). The World Health Organization (WHO) argues that to be effective, this type of communication should be (a) accessible and applicable; (b) credible and reliable; (c) relevant, (d) timely, and (e) understandable by decision-makers (World Health Organization, n.d.).

Renata Schiavo (2014) adds a refreshing perspective, explaining that one of the main goals of health communication should be to "engage, empower, and influence" individuals and communities (p. 5). In other words, the ultimate goal of health communication is to promote behavioural maintenance or change that aligns with the promotion of individuals' health.

Within the framework of a pandemic and despite the absolute value of the different levels of health communication involving many different agents (interpersonal, group,

and other), the social level demands more significant effort. It is where the most noticeable results are expected. Kreps (2001) describes this level of communication as focused on creating, disseminating, and using health information communicated through various media to a wide range of professional and lay audiences in society, which influence health education and promotion practices (p. 235).

Thus, the focus should be more robust at this level because it can impact a wide range of audiences (Goldberg et al., 2015). Let us think about one of the health crises over the last decade, such as the ebola outbreak in 2014, for example. It is enough to understand how essential health communication at the social level is to inform populations from various countries, condition behaviours and thus make the population an ally in maintaining their health security, promoting the containment of an epidemic through preventive behaviours. It was also within this level of communication that what may have been the most transversal health communication campaign in the world — the campaign against covid-19 — was put into practice.

However, for health communication campaigns to be efficient, they must be well designed and rigorously targeted, through the most appropriate channels, and with a frequency that allows the message to be received, assimilated, and remembered (Abroms & Maibach, 2008, p. 221). As far as covid-19 is concerned, we cannot claim there has been a real campaign, despite the efforts made in this sense, particularly on the part of the WHO. Furthermore, the pandemic's extent and the lack of scientific evidence on the virus' nature and behaviour led to many assumptions of what should be a health communication being forgotten, lost in the flood of uncertainty. The zika epidemic between 2015 and 2016 had proven a tendency to spread misinformation[1] in the absence of confirmed information about the disease (Vraga & Jacobsen, 2020).

Given this health crisis scenario, with no solid scientific evidence to guide the political decision safely and clearly, society reacted, relentlessly seeking more information to adjust its behaviour and thus ensure its safety (Paakkari & Okan, 2020). As a result, the news media have become extremely important as indispensable partners in response to this public health emergency and as mediators between governments, health institutions and the public (Mheidly & Fares, 2020). Indeed, the public seeks "accurate information, sound scientific facts, government decisions and general public reactions" (Mheidly & Fares, 2020, p. 411) through the media and, increasingly, social media (Newman, 2020): the increase in news consumption during the covid-19 pandemic illustrates their centrality (Casero-Ripolles, 2020).

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[1] The Portuguese term "desinformação" covers three types of information disorder: disinformation, misinformation, and mal-information; all these phenomena differ on the axis of falseness and intent to harm (Wardle & Derakhshan, 2017). Disinformation is false information deliberately created to harm. Misinformation is also false information but not intended to harm. Malinformation is based on reality but does not reflect the entirety of history or perspectives and is used to inflict harm on people, organizations, or countries. In the Portuguese version of this article, we use the concept of "desinformação" with the meaning of misinformation.

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Vaccination — A Major Challenge for Health Communication

The vaccination process against covid-19 launched by the European Union on December 27, 2020, will be remembered as a response to the most significant challenge that humanity has faced in the first years of this century (Jeyanathan et al., 2020).

The communication of this campaign was itself an exceptional case that is worth evaluating. Across Europe, in a concerted fashion, official sources, media and society turned their attention to the vaccine. This long-awaited solution was capitalized politically by the European Commission and the governments of the European Union's member countries. However, the communicative challenge posed by the vaccination campaign goes far beyond the political arena.

Communication was a crucial strategy in public health (Rudd & Baur, 2020), and its role in the vaccination campaign was immediately acknowledged as essential. In fact, within health communication, vaccination was a challenge in itself. It was one of the most studied topics due to its association with critical misinformation phenomena, which triggered anti-vaccination movements.

One of the causes of this problem was a scientific article published by Andrew Wakefield and other specialists in the renowned scientific journal *The Lancet* in 1998. The paper linked the MMR vaccine (against measles, epidemic parotitis, and rubella) to autism. Although the article was a case study with a sample of only 12 children, its results had an enormous impact on the community, namely due to the media coverage it received. Thus, between 2003 and 2004, the vaccination rate against measles, epidemic parotitis and rubella in 2-year-old children in the United Kingdom dropped to around 80% (Editorial Board, 2012). Although *The Lancet* removed the discredited article from its archives in 2010, the anti-vaccination movement kept growing (Arif et al., 2018).

As a result, as Renata Schiavo (2020) stresses, the media's involvement in this process becomes fundamental, considering the role of journalists in ensuring accurate and evidence-based media coverage as very important and "training scientists and government agencies to discuss in plain language the benefits of a future vaccine for the COVID-19 with the media" (p. 74). Today, with the massive proliferation of online information, the risks associated with communication on vaccination are even higher. Data remains in an online environment, indelible, regardless of its quality, with consequences extending to various domains and hard to manage (Suiter & Culloty, 2021). Therefore, "counteracting misinformation on vaccines by health authorities is part of the solution" (Arif et al., 2018, p. 10).

Thus, the responsibility that falls on political and health authorities is exceptionally high. Apart from adequately promoting the reception, distribution and administration of the vaccine, they will have to rigorously and cautiously facilitate the communication process about the vaccine; otherwise, instead of ensuring the much-needed adherence to vaccination, they will "increase misconceptions or reduce the intention to vaccinate" (Nyhan et al., 2014, p. e835).

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In their favour, official sources rely on the willingness of most citizens to be inoculated. According to a European study published as recently as 2020, 75% of the Portuguese admitted they want to be vaccinated (Neumann-Böhme et al., 2020). Communication about vaccination was therefore starting favourably.

Official Sources and Strategic Communication

In the media space, sources are the origin of the information we read, see and hear. According to Hall et al. (1978), the authoritative and objective sources represent the prominent social institutions, institutional power with representative status (members of parliament, ministers, trade unions, etc.), and experts.

Among the existing sources, the official ones hold a dominant position (Araújo, 2017; Lopes et al., 2015; Ribeiro, 2006; Santos, 1997). Studies in Portugal have revealed an elite of organized sources that define the health news (Araújo, 2017; Lopes et al., 2011), influencing the production of three out of 10 pieces of information on this subject in the national press (Magalhães, 2012).

The sources seek to increase their visibility, set the public agenda, gain support or adherence to ideas, prevent or repair damages, neutralize opponents' interests, and create a positive public image (Pinto, 2000, p. 280). In other words, sources in general, and the authorities that we recognize as official sources, in particular, use their communication potential strategically, intentionally to fulfil a specific mission, crossing areas such as management, marketing, advertising and public relations (Hallahan et al., 2007).

Hence, strategic communication corresponds to unifying different communication actions designed to help achieve the strategic goals of a given entity, using the available forms of communication to meet its objectives, its tactics and action plans defining each of these forms (Carrillo, 2014).

Translating this to the challenge of implementing a generalized vaccination campaign that starts within a pandemic, we realize that adopting a communication strategy logic is essential for the authorities involved in the vaccination process to achieve their goals. Using media advisory strategies allows them to influence public opinion through traditional media and use "disintermediated" strategies (Eldridge et al., 2019; Lévy, 1998), namely in the digital environment, which facilitate a closer "dialogue" with different groups of society.

Methodology

This study aimed to understand the communication strategies adopted by official national sources to communicate on the covid-19 vaccination. It is part of a larger project seeking to analyze this topic through the media coverage of the covid-19 vaccination in the Portuguese media (namely in the news services of open signal generalist channels

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and the newspapers *Público* and *Jornal de Notícias*) and the strategic communication promoted by Portuguese and European official sources.

The relevance of digital communication in the current media and information panorama is undeniable (Neuman, 2016; Reyna et al., 2018), so official sources are increasingly focusing on this type of communication by boosting their websites and their pages in the most active and closest to the public online social networks (Statista, 2021). In Portugal, users spend an average of 96 minutes per day browsing, which rises to 135 minutes among the youngest. Facebook still leads the chart, but Instagram is gaining ground, as 67% of Portuguese people, in 2020 used these platforms to consume information (Marktest, 2020). Between 2015 and 2020, according to the *Reuters Institute Digital News Report* 2020 (Newman et al., 2020), television has been challenged by online and social media, and smartphone use has grown steadily. From the standpoint of organizations with an online social media presence, 70% have a corporate page on Facebook, followed by LinkedIn (54%), Youtube (44%) and Twitter (42%). At the same time, Instagram stands out as the platform with the most significant growth potential (NOS, n.d.).

Building on these indicators, we analyzed the official websites and the online social networks accounts (Facebook, Instagram, Twitter and LinkedIn) of Directorate-General for Health (Direção-Geral da Saúde, DGS), government/prime minister; National Authority of Medicines and Health Products (Autoridade Nacional do Medicamento e Produtos de Saúde I.P., Infarmed); Ministry of Health; National Health Service (Serviço Nacional de Saúde, SNS). The selection of sources focused on identifying the authorities directly involved in the pandemic management and the public health response (Table 1).

OFFICIAL SOURCE	WEBSITE	ONLINE SOCIAL NETWORKS —NUMBER OF FOLLOWERS IN JANUARY 2021
Directorate-General for Health	https://www.dgs.pt/	Facebook: 701,400
		Instagram: 22,500
		Twitter: 47,000
		LinkedIn: 2,600 (without posts)
Government/prime minister	https://www.portugal.gov.pt/pt/gc22	Facebook: 77,400
		Instagram: 22,500
		Twitter: 47,000
		LinkedIn: 2,600 (without posts)
Infarmed	https://www.infarmed.pt/	Facebook: 16,500
		Instagram: not applicable
		Twitter: 6,300
		LinkedIn: 42,300
Ministry of Health	https://covid19.min-saude.pt/	Not applicable
National Health Service	https://www.sns.gov.pt/	Facebook: 266,300
		Instagram: 173,000
		Twitter: 30,000
		LinkedIn: not applicable

Table 1 Portuguese official sources analyzed between December 21, 2020, and January 21, 2021

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For the Ministry of Health, we chose to analyze the website dedicated to covid-19, which included a microsite devoted to vaccination, since this was the Ministry of Health's privileged platform for communicating with society on this topic. Moreover, the ministry did not have an account on online social networks.

The content related to covid-19 vaccination was mapped, selected and analyzed, totalling 134 occurrences on official websites and 297 posts on online social networks from December 21, 2020 — the day the first vaccine was authorized by the European Union — to January 21, 2021.

Analysis Grids and Variables

To analyze the content, we applied two analysis grids with a standard set of variables, adjusted according to the type of content analyzed (content published on a website or a post published on an online social network).

The grids were designed to identify the main characteristics of the content published by official sources, according to the variables presented in Table 2.

Websites	Online social networks	Description
Official source	Official source	Name of the official source providing the information
Not applicable	Social network	Name of the online social network where the content was published
Type of content	Type of content/multimedia	Communication support adopted (the categories of this variable were adjusted to the platforms — websites or social networks)
Public	Not applicable	Society group targeted with the content (assessed from the perspective of the recipient)
Framework	Framework	Tone of the content
Topic	Topic	Areas of intervention and angles of approach on vaccination
Protagonist	Protagonist	Individual who plays a key role in the content
Not applicable	Hypertextuality	Links available for further information

Table 2 Variables used in the analysis grids applied in the study and their descriptions

The data collected were then coded and categorized in SPSS, allowing for simple frequency analyses and crossing of variables, which contributed to a more extensive and in-depth understanding of the form, content and objectives of the communication strategies of the official sources selected on the topic under study.

Outcomes

Presence of Official Sources in Online Channels

More than half of our sample consisted of content communicated by the SNS through its website and online social networks pages. Looking at the websites, Infarmed

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is next on the list of most valuable sources for communicating new information on covid-19 vaccination, with a percentage of 20%, followed by the government (13%), the Ministry of Health's website dedicated to the pandemic and vaccination (9%) and, finally, the DGS, whose content on this topic was only 8%. The behaviour of sources in online social networks is, however, different. The government holds a more prominent place, as it is the second most frequent source, accounting for 12% (Table 3).

	Websites		**Online Social Networks**	
	Frequency	Percentage	Frequency	Percentage
National Health Service	67	50.0	223	75.1
Infarmed	27	20.1	21	7.1
Government	18	13.4	36	12.1
Ministry of Health /Covid-Vac (Ministry of Health's website on covid and vaccination)	12	9.0	N/A	N/A
Directorate-General for Health	10	7.5	17	5.7
Total	134	100.0	297	100.0

Table 3 *Covid-19 vaccination content published by official national sources on their websites and online social networks*

Portuguese official sources focused their communication efforts on online social networks on Twitter (Table 4). The Portuguese government most used this platform, posting approximately 70% of its vaccination-related content on Twitter. However, the SNS added a higher number of occurrences on this network (*n* = 93). It is worth mentioning that the DGS opted for a different platform, favouring the use of Facebook (47%), although with a reduced number of posts in the sum of the four networks analyzed (*n* = 17).

		Online social networks			
		Facebook	Instagram	Twitter	LinkedIn
Government	Frequency	6	5	25	0
	Percentage	16.7	13.9	69.40	0
Directorate-General for Health	Frequency	8	4	5	0
	Percentage	47.1	23.5	29.40	0
Infarmed	Frequency	5	0	9	7
	Percentage	23.8	0.0	42.90	33.30
National Health Service	Frequency	74	56	93	0
	Percentage	33.2	25.1	41.70	0
Total	Frequency	93	65	132	7
	Percentage	31.3	21.9	44.40	2.40

Table 4 *Distribution of posts on covid-19 vaccination from official sources per online social network*

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Types of Content and Target Audiences

About 65% of the content produced by the official sources under study fall in the category of "institutional news", with a very significant distance from the category "press release" (11%) that follows it (Table 5). Formal documents of official content account for 6.7%, followed by frequently asked questions (FAQ) with a percentage of 3.7%. We find content types such as information leaflets (2.2%), video (only 1.5%), and others with lower rates.

	Frequency	Percentage
Institutional news	87	64.9
Press release	15	11.2
Document	9	6.7
Frequently asked questions (FAQ)	5	3.7
Text block	3	2.2
Interactive	3	2.2
Information leaflet/poster	3	2.2
Newsletter	2	1.5
Video	2	1.5
Intervention	1	0.7
Other	4	3.0

Table 5 *Types of content about covid-19 vaccination published on official national sources websites*

Text is the most common type of content in the posts published by the analyzed sources on their online social networks pages (60%), followed by banners (33%). The use of this type of content, with hints of advertising language, represents a significant result insofar as it disrupts the informative, almost journalistic language used, for instance, on websites. The banners frequently combine, in the same image, photo or illustration with persuasive messages and may derive from multimedia advertising campaigns (Table 6).

	Frequency	Percentage
Text	252	57.1
Banners	146	33.1
Photography	23	5.2
Photo gallery	9	2.0
Video	6	1.4
Infographics	3	0.7
Live/livestream	2	0.5

Table 6 *Types of content published in the online social networks of official national sources*

Note. Since online social networks content tends to have more than one type of content, we categorized the two dominant content types in each post. Therefore, the total number of records in this table exceeds the total number of posts analyzed.

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It is worth mentioning that within the scope of the website's analysis, we also assessed the target public of the published contents and concluded that 78.4% ($n = 105$) of the information was aimed at the general public. The contents addressed to health professionals and entities involved in the vaccination process added up to 11% ($n = 14$), along with the information made available to the media. This variable did not apply to online social networks content, as such content is expected to target a wider audience.

Framework

The official sources preferred an informative approach when communicating about vaccination against covid-19, followed by a positive direction, which accounted for 18% of the content published on the websites and 16% of the content posted on the social networks (Table 7). The educational framing was postponed to a later plan, adopted in only 4% of the cases concerning the websites and having no expression in the posts of the analyzed social networks. The contents with a persuasive or defensive approach were infrequent. However, it is essential to mention the DGS, which, among all sources, made the most use of the compelling approach, particularly in online social networks.

	Websites		Online social networks	
	Frequency	Percentage	Frequency	Percentage
Newsletter	98	73.1	238	80.1
Positive	24	17.9	46	15.5
Educational	5	3.7	1	0.3
Persuasive/defensive	4	3.0	12	4.0
Other/ not applicable	3	2.2	0	0

Table 7 *Framework of content published on websites and online social networks*

Topics

The content provided by official sources focused primarily on the routine administration of the SARS-Cov-2 vaccine. This topic underpinned one-third of the content published on the websites and about 70% of the posts published on the social networks we monitored. The groups defined as priority groups for their reception (16%) received special attention from the Portuguese official websites (16%). Still, curiously, the same did not happen on the online social networks, which only addressed this topic three times. More than 13% of the official sources' communication addressed the vaccine from a generic perspective (giving an overview of the subject, without going into depth), both on websites and online social networks, with topics such as vaccine safety and the authorization for its administration remaining in the background (Table 8).

	Websites		**Online social networks**	
	Frequency	Percentage	Frequency	Percentage
Administration	42	31.3	206	69.4
Priority groups	22	16.4	3	1
Generic approach	18	13.4	39	13.1
Technical and scientific information	12	9	7	2.4
Distribution	9	6.7	13	4.4
Deadlines	5	3.7	0	0
Authorization of the vaccine	5	3.7	9	3
Vaccine safety	4	2.9	0	0
Portraits: national/international	4	3	1	0.3
Prevention	2	1.5	0	0
Failure to meet deadlines	2	1.5	0	0
Difficulties in distribution	2	1.5	0	0
Political decisions	1	0.7	1	0.3
Decisions by health authorities	1	0.7	0	0
Acknowledgements	0	0	9	3
Fact-check	0	0	6	2
Other	3	2.2	3	0.9
Not applicable	2	1.5	0	0

Table 8 *Themes of the content on covid-19 vaccination published on websites and online social networks*

Protagonists

More than half of the content about vaccination published on the websites of the primary official sources does not focus on individuals who can assume a protagonist role (55%). As for online social networks, 77% of the content can relate to one or more protagonists (Table 9).

	Websites		**Online social networks**	
	Frequency	Percentage	Frequency	Percentage
Official sources' representatives	34	25.4	60	20.2
Healthcare professionals	13	9.7	40	13.5
Citizens	1	0.7	5	1.7
Various	13	9.7	116	39.1
Other	0	0	7	2.4
Without protagonist	73	54.5	69	23.2

Table 9 *Protagonists in content about covid-19 vaccination published on websites and online social networks*

When there are protagonists, the official sources' representatives take a prominent role on the websites, unsurprisingly (with a presence of 25% compared to the total and 56% compared to the contents with a protagonist). Citizens are outside the scope of these sources (they are not represented in 1% of the total contents published on the websites,

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and in the online social networks, they remain below 2%). Healthcare professionals are in the second visibility line on the websites (10%) and online social networks (14%).

Official sources do not enjoy the same prominence on online social networks. The prominence is chiefly shared (39%) among different players, and the posts that give an exclusive stage to official sources' representatives are limited to about one-fifth of the cases (20%).

Hypertextuality

Only 64% of the posts about vaccination published on social networks show signs of hypertextuality. About 40% of the publications redirect followers to the official source websites, and 18% are content reposts, a strategy typically used on Twitter (Table 10).

	Frequency	Percentage
Official websites	116	39.1
Repost	53	17.8
Other international platforms	12	4
Information developed	6	2
Online social networks	1	0.3
Other resources	1	0.3
Not applicable	108	36.4

Table 10 *Hypertextuality of posts on covid-19 vaccination published by official sources on the respective online social networks*

Discussion

Our results show that the SNS is the official source that most favours communication on vaccination in the digital environment in the channels analyzed, through a fruitful publication of content on its website and the continuous publication of information on online social networks. Considering that society perceives the SNS as the enforcer of the Ministry of Health, this result seems expectable. It was an indicator of "good communicative health" on the SNS when it was constantly tested.

It is worth mentioning that the SNS was more proficient in producing and publishing content than the other official national sources analyzed. It stood out for employing a logic of proximity, echoing the progress of vaccination by region, in a clear intention to let all citizens, from north to south of the country and the islands, know that the vaccine would reach all areas. Titles such as "Vaccination Starts Today for Health Professionals in Tâmega and Sousa" and "Vaccination at ULS of Guarda", identified in institutional news items on the SNS website, are proof of that. In other words, this is the source closest to citizens and the one most aware of the need to decentralize information. Therefore, the hospital centres and health units of the SNS can provide content that this source will replicate.

Still, when selecting online social networks to promote content on vaccination, this source favours Twitter. So do the government and Infarmed. The Ministry of Health does not have an account on this social network.

Twitter has around 199,000,000 daily users. In the first quarter of 2020, when the pandemic was decreed, in March, daily active users grew from 133,000,000 in the first quarter of 2020 to 162,000,000 users in the last quarter, up about 22 percent (Elfira & Indrawan, 2021).

However, we know that this is not Portugal's most used online social network. Facebook and Instagram surpass it. According to a Marktest (2020) report, when asking the Portuguese which online social networks they know, Facebook has the most spontaneous references among respondents by 99.6%, followed by Instagram by 87.4% and Twitter by 60.1%.

Thus, why do official sources publish more insistently on Twitter? We can explore two interpretations. The first has to do with the features of this network which predispose to the publication of shorter but more frequent posts, making it possible to inflate the number of posts published. The second has to do with the audience: sources prefer to use this network because, in fact, more than communicating directly with citizens, they seek to speak with a vital target segment — journalists. We know that journalists are specially tuned to this network, following closely what official sources publish and looking for news information (Parmelee, 2013). Therefore, we point out that official sources may use online social networks as (yet) another media relations tool.

In the opposite direction to the SNS, the government and Infarmed, we find the DGS. This institution favoured Facebook, which is not surprising since it has 701,400 followers on this platform and only 47,000 followers on Twitter. This option allows the DGS to prioritize direct communication with citizens through online social networks, enabling more effectively delivering messages with a solid intent to induce behaviours and encourage vaccination. The results support this thesis, revealing that DGS published two-thirds of the posts with a persuasive tone. Still, the DGS may be underusing its communication capacity on Facebook since the total number of posts published on vaccination was relatively small.

Most of the content official sources published on their websites and online social networks were news-based. Besides the fact that 65% of the content disclosed by official sources on the websites were institutional news, we noted that, on social networks, posts are often composed of informative texts complemented by photos. Therefore, a news language underlying the sources' contents in the digital environment may derive from the long tradition of media relations associated with the Portuguese official sources.

While the journalistic style is desirable in media relations work, it may not be the most adequate when the intention is to inform and persuade the message receivers to adopt a particular behaviour. Within the scope of our analysis of the online social networks contents, we realized that using a language closer to advertising only accounts

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for approximately 30% of the posts published on the networks, and these translate into banners similar to advertisements, duly adapted to the media, and adopted mainly by the SNS.

Considering the responsibilities of the official sources under analysis, one could have expected a more substantial effort to produce and promote content with an educational approach, more focused on educating and clarifying the population on topics that may compromise their adherence to vaccination. However, educational content did not find space on online social networks and accounted for only 4% of the content published on the websites.

Before the vaccine arrived in Portugal, 75% of the Portuguese assumed they wanted to be vaccinated (Neumann-Böhme et al., 2020). A significant percentage pointed to fears about the vaccine's safety and possible side effects. However, this topic was one of the least covered by official sources when communicating in the digital environment. Vaccine safety was the focus of only four pieces of all content published on websites. The topic was almost wholly excluded from communication on vaccination, on the online social networks, during the period under analysis, reflecting an apparent avoidance of the subject.

In contrast, the strategy of the official sources focused on administration as proof of the vaccination campaign's success. Administration, priority groups and generic approaches about the vaccine represent the dominant topics actively promoted by official sources in the digital outlets they control. In the future, we intend to assess to what extent these choices of topics correlate with the thematic approaches taken by journalists because we observe the influence of media relations techniques and objectives within the digital communication strategies of the sources under study.

The representatives of the official sources most often take the leading role in the contents published on the websites and, even on the online social networks, they take a prominent place in one-fifth of the posts, surpassing the health professionals, whose prominence lies between 10% and 14%. The office holders from the official sources analyzed are presented as the central agents of the vaccination process in a straightforward exercise of strategic communication with political intentions, which may reap dividends with public opinion.

Conclusions

Our work suggests that the primary Portuguese official sources lead the covid-19 vaccination process, which falls into three key topics — vaccine administration, defining priority groups and generic approaches. They do so through institutional news with a mostly informative tone on the websites. They use the same technique on the online social networks' posts that rely on texts and photos, including hyperlinks that direct followers to official sites, often European entities.

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According to our results, the SNS takes over as the main interlocutor of the Portuguese when it comes to covid-19 vaccination. However, despite the SNS being particularly prolific in the digital environment, doubts remain about this official source's degree of coordination with the other analyzed authorities. In the future, it is necessary to evaluate the communication on vaccination of these sources from a multimedia perspective.

Media relations still strongly influence the communication promoted by official national sources in the digital environment. On social networks, sources communicate through Twitter, possibly to set traditional media's agenda and influence opinion-makers, as citizens tend to prefer networks with other attributes.

The intense focus on the vaccine administration could suggest that the sources have let themselves be swept along by the media's current affairs flow, centred on it. On the other hand, as we know that sources tend to be the main determinants of the information conveyed by the media, we suggest that the confluence on this topic is a strategic choice with political purposes. The administration of the vaccine represents an unprecedented success of European policies and influences the national policies of each European Union country. Capitalizing on this success means improving the political reputation of official sources and their representatives. In Portugal, this situation was made even more evident by the proximity of the Portuguese presidency of the Council of the European Union, starting a few days after the vaccination began.

The focus on vaccine administration went hand in hand with the undervaluation of other topics equally crucial from a health perspective but possibly less appealing from a political perspective, namely vaccine safety and possible distribution problems arising from lack of supply. Portuguese official sources did not actively and significantly promote content on these two essential topics in the digital channels analyzed. However, it was known that safety and side effects were of concern to some citizens and that the supply capacity of the pharmaceutical companies producing the vaccine might fall short. Assuming that these options may have been intentional, they suggest that official sources approach the communication process on vaccination from a political communication perspective and not from a health communication perspective.

Considering that health communication aims to "engage, empower and influence individuals and communities" (Schiavo, 2014, p. 5), we conclude that, during the period of analysis, official sources promoted conservative forms of communication, potentially missing the opportunity to foster a more direct, educational, interactive and personalized communication in the digital environment.

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References

Abroms, L. C., & Maibach, E. W. (2008). The effectiveness of mass communication to change public behavior. *Annual Review of Public Health*, *29*(1), 219–234. https://doi.org/10.1146/annurev.publhealth.29.020907.090824

Araújo, R. (2017). *Dinâmicas de construção do noticiário de saúde: Uma análise da imprensa generalista portuguesa* [Doctoral dissertation, Universidade do Minho]. RepositóriUM. http://hdl.handle.net/1822/45761

Arif, N., Al-Jefri, M., Bizzi, I. H., Perano, G. B., Goldman, M., Haq, I., Chua, K. L., Mengozzi, M., Neunez, M., Smith, H., & Ghezzi, P. (2018). Fake news or weak science? Visibility and characterization of antivaccine webpages returned by Google in different languages and countries. *Frontiers in Immunology*, *9*, Article 1215. https://doi.org/10.3389/fimmu.2018.01215

Carrillo, M. V. (2014). Comunicação estratégica no ambiente comunicativo das organizações atuais. *Comunicação e Sociedade*, *26*, 71–80. https://doi.org/10.17231/comsoc.26(2014).2025

Casero-Ripolles, A. (2020). Impact of covid-19 on the media system. Communicative and democratic consequences of news consumption during the outbreak. *El Profesional de la Información*, *29*(2), Article e290223. https://doi.org/10.3145/epi.2020.mar.23

Center for Systems Science and Engineering. (2021, January 23). *Covid-19 dashboard*. Johns Hopkins Coronavirus Resource Center. https://coronavirus.jhu.edu/map.html

Editorial Board. (2012, December 7). *Measles vaccination rates in UK recover after 14 years*. Vaccines Today. https://www.vaccinestoday.eu/stories/measles-vaccination-rates-in-uk-recover-after-14-years/

Eldridge, S. A., II, García-Carretero, L., & Broersma, M. (2019). Disintermediation in social networks: Conceptualizing political actors' construction of publics on Twitter. *Media and Communication*, *7*(1), 271–285. https://doi.org/10.17645/mac.v7i1.1825

Elfira, T., & Indrawan, A. (2021). *During the pandemic, twitter users grew rapidly*. VOI. https://voi.id/en/technology/48500/during-the-pandemic-twitter-users-grew-rapidly

Fielding, J. (2020). Good communication will help beat covid-19. *The Hill*. https://thehill.com/opinion/healthcare/490410-good-communications-will-help-beat-Covid-19

Finset, A., Bosworth, H., Butow, P., Gulbrandsen, P., Hulsman, R. L., Pieterse, A. H., Street, R., Tschoetschel, R., & van Weert, J. (2020). Effective health communication – A key factor in fighting the covid-19 pandemic. *Patient Education and Counseling*, *103*(5), 873–876. https://doi.org/10.1016/j.pec.2020.03.027

Goldberg, A. B., Ratzan, S. C., Jacobson, K. L., & Parker, R. M. (2015). Addressing ebola and other outbreaks: A communication checklist for global health leaders, policymakers, and practitioners. *Journal of Health Communication*, *20*(2), 121–122. https://doi.org/10.1080/10810730.2015.1007762

Guedes, N. (2020, December 11). *Há mais de 70 anos que Portugal não tinha tantos mortos como em 2020*. TSF. https://www.tsf.pt/portugal/sociedade/ha-mais-de-70-anos-que-portugal-nao-tinha-tantos-mortos-como-em-2020-13127678.html

Hall, S., Critcher, C., Jefferson, T., Clarke, J. & Roberts, B. (1978). *Policing the crisis. Mugging, the state, and law and order*. Holmes & Meier Publishers.

Hallahan, K., Holtzhausen, D., van Ruler, B., Verčič, D., & Sriramesh, K. (2007). Defining strategic communication. *International Journal of Strategic Communication*, *1*(1), 3–35. https://doi.org/10.1080/15531180701285244

Ishikawa, H., & Kiuchi, T. (2010). Health literacy and health communication. *BioPsychoSocial Medicine*, *4*, 1–5. https://doi.org/10.1186/1751-0759-4-18

Jeyanathan, M., Afkhami, S., Smaill, F., Miller, M. S., Lichty, B. D., & Xing, Z. (2020). Immunological considerations for covid-19 vaccine strategies. *Nature Reviews Immunology*, *20*(10), 615–632. https://doi.org/10.1038/s41577-020-00434-6

Kreps, G. L. (2001). The evolution and advancement of health communication inquiry. *Annals of the International Communication Association*, *24*(1), 231–253. https://doi.org/10.1080/23808985.2001.11678988

Lévy, P. (1998). A revolução contemporânea em matéria de comunicação (J. M. da Silva, Trans.). *Revista FAMECOS*, *5*(9), 37–49. https://doi.org/10.15448/1980-3729.1998.9.3009

Lopes, F., Marinho, S., Fernandes, L., Araújo, R., & Gomes, S. (2015). A saúde em notícia na imprensa portuguesa entre setembro de 2010 e junho de 2013. In F. Lopes, T. Ruão, S. Marinho, Z. P. Coelho, L. Fernandes, R. Araújo, & S. Gomes (Eds.), *A saúde em notícia: Repensando práticas de comunicação* (pp. 55–79). CECS.

Lopes, F., Ruão, T., Marinho, S., & Araújo, R. (2011). Jornalismo de saúde e fontes de informação, uma análise dos jornais portugueses entre 2008 e 2010. *Derecho a Comunicar - Revista Científica de la Associación de Derecho a la Información*, (2), 101–120. http://132.248.9.34/hevila/Derechoacomunicar/2011/no2/6.pdf

Magalhães, O. E. (2012). *Comunicação de saúde e fontes – O caso da Faculdade de Medicina da Universidade do Porto* [Master's thesis, Universidade do Porto]. Repositório Aberto. https://repositorio-aberto.up.pt/handle/10216/66407

Marktest. (2020, October 27). *Quem usa e o que faz nas redes sociais?* https://www.marktest.com/wap/a/n/id~26c7.aspx

Mheidly, N., & Fares, J. (2020). Leveraging media and health communication strategies to overcome the covid-19 infodemic. *Journal of Public Health Policy*, *41*(4), 410–420. https://doi.org/10.1057/s41271-020-00247-w

Neuman, W. R. (2016). *The digital difference: Media technology and the theory of communication effects*. Harvard University Press.

Revista Lusófona de Estudos Culturais / Lusophone Journal of Cultural Studies, Vol. 8, No. 2, 2021

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Neumann-Böhme, S., Varghese, N. E., Sabat, I., Barros, P. P., Brouwer, W., van Exel, J., Schreyögg, K., & Stargardt, T. (2020). Once we have it, will we use it? A European survey on willingness to be vaccinated against covid-19. *The European Journal of Health Economics*, *21*(7), 977–982. https://doi.org/10.1007/s10198-020-01208-6

Newman, N. (with Fletcher, R., Schulz, A., Andı, S., & Nielsen, R. K). (2020). *Reuters Institute digital news report 2020*. Reuters Institute. https://reutersinstitute.politics.ox.ac.uk/sites/default/files/2020-06/DNR_2020_FINAL.pdf

NOS. (n.d.). *NOS divulga terceiro estudo: Portugal tech insights 2020*. https://www.nos.pt/institucional/PT/media/em-destaque/Paginas/NOS-divulga-terceiro-estudo-Portugal-Tech-Insights-2020.aspx

Nyhan, B., Reifler, J., Richey, S., & Freed, G. L. (2014). Effective messages in vaccine promotion: A randomized trial. *Pediatrics*, *133*(4), e835–e842. https://doi.org/10.1542/peds.2013-2365

Paakkari, L., & Okan, O. (2020). Covid-19: Health literacy is an underestimated problem. *The Lancet Public Health*, *5*(5), e249–e250. https://doi.org/10.1016/S2468-2667(20)30086-4

Parmelee, J. H. (2013). Political journalists and Twitter: Influences on norms and practices. *Journal of Media Practice*, *14*(4), 291–305. https://doi.org/10.1386/jmpr.14.4.291_1

Pinto, M. (2000). Fontes jornalísticas: Contributos para o mapeamento do campo. *Comunicação e Sociedade*, *2*, 277–294. https://doi.org/10.17231/comsoc.2(2000).1401

Reyna, J., Hanham, J., & Meier, P. (2018). The internet explosion, digital media principles and implications to communicate effectively in the digital space. *E-Learning and Digital Media*, *15*(1), 36–52. https://doi.org/10.1177/2042753018754361

Ribeiro, V. (2006). *Fontes sofisticadas de informação: Análise do produto jornalístico político da imprensa nacional diária de 1995 a 2005* [Master's thesis, Universidade do Porto]. Repositório Aberto. http://hdl.handle.net/10216/13047

Rudd, R., & Baur, C. (2020). Health literacy and early insights during a pandemic. *Journal of Communication in Healthcare*, *13*(1), 13–16. https://doi.org/10.1080/17538068.2020.1760622

Santos, R. (1997). *A negociação entre jornalistas e fontes*. Minerva.

Schiavo, R. (2014). Health communication in health disparities settings. *Journal of Communication in Healthcare*, *7*(2), 71–73. https://doi.org/10.1179/1753806814Z.00000000073

Schiavo, R. (2020). Vaccine communication in the age of covid-19: Getting ready for an information war. *Journal of Communication in Healthcare*, *13*(2), 73–75. https://doi.org/10.1080/17538068.2020.1778959

Statista. (2021, October). *Most popular social networks worldwide as of October 2021, ranked by number of active users*. https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/

Suiter, J., & Culloty, E. (2021). *Disinformation and manipulation in digital media: Information pathologies*. Routledge.

Vraga, E. K., & Jacobsen, K. H. (2020). Strategies for effective health communication during the coronavirus pandemic and future emerging infectious disease events. *World Medical & Health Policy*, *12*(3), 233–241. https://doi.org/10.1002/wmh3.359

Wardle, C., & Derakhshan, H. (2017). *Information disorder*. Council of Europe

Revista Lusófona de Estudos Culturais / Lusophone Journal of Cultural Studies, Vol. 8, No. 2, 2021

Vaccination Against Covid-19 · Olga Estrela Magalhães, Clara Almeida Santos, Catarina Duff Burnay, Rita Araújo, Felisbela Lopes & Ana Teresa Peixinho

World Health Organization. (n.d.). *WHO principles for effective communications.* https://www.who.int/about/communications/principles

World Health Organization. (1998). *Health promotion glossary.* https://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf?ua=1

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