Article

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The agency of autistic students in educational research

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Abstract

This study analyzes the agency of autistic students in academic research on autism and Basic Education. Based on a review of 57 articles available in Edubase and the Scientific Electronic Library Online (SciELO), using content analysis procedures, we observed a growth in publications from the second half of the 2010s, with a predominance of case studies. However, the limited effective participation of autistic individuals as central subjects in the studies reveals that scientific production still tends to speak about them, rather than with them, reproducing the biomedical model of disability and marginalizing their actions. These results highlight the gap between the discourse of inclusion and the practice of educational research, underscoring the need for epistemological shifts that recognize autistic individuals as active agents in the construction of knowledge about their own schooling.

Keywords: Autism. Basic Education. Social model of disability. Literature review.

Protagonismo dos estudantes autistas em pesquisas educacionais

Resumo

Este estudo analisa o protagonismo dos estudantes autistas em pesquisas acadêmicas sobre autismo e Educação Básica. A partir da revisão de 57 artigos disponíveis na Edubase e na *Scientific Electronic Library Online* (SciELO), utilizando procedimentos de análise de conteúdo, observou-se o crescimento de publicações a partir da segunda metade da década de 2010, com predominância de estudos de caso. Entretanto, a baixa participação efetiva de autistas como sujeitos centrais nos estudos revela que a produção científica ainda tende a falar *sobre* eles, e não *com* eles, reproduzindo o modelo biomédico da deficiência e marginalizando suas ações. Esses resultados tensionam a distância entre o discurso da inclusão e a prática da pesquisa educacional, evidenciando a necessidade de deslocamentos epistemológicos que reconheçam os autistas como agentes ativos na construção do conhecimento sobre sua própria escolarização.

Palavras-chave: Autismo. Educação Básica. Modelo social da deficiência. Revisão de literatura.

Protagonismo de los estudiantes autistas en investigaciones educativas

Resumen

Este estudio analiza el protagonismo de los estudiantes autistas en investigaciones académicas sobre autismo y Educación Básica. A partir de la revisión de 57 artículos disponibles en Edubase y en la Scientific Electronic Library Online (SciELO), utilizando procedimientos de análisis de contenido, se observó el crecimiento de publicaciones a partir de la segunda mitad de la década de 2010, con predominio de estudios de caso. Sin embargo, la baja participación efectiva de las personas autistas como sujetos centrales en los estudios revela que la producción científica aún tiende a hablar sobre ellas, y no con ellas, reproduciendo el modelo biomédico de la discapacidad y marginando sus acciones. Estos resultados tensionan la distancia entre el discurso de la inclusión y la práctica de la investigación educativa, evidenciando la necesidad de desplazamientos epistemológicos que reconozcan a las personas autistas como agentes activos en la construcción del conocimiento sobre su propia escolarización.

Palabras clave: Autismo. Educación Básica. Modelo social de la discapacidad. Revisión de literatura.

Introduction

At the outset of a seminal text, Lígia Amaral (1998) invites readers to reflect on differences and prejudice within the school environment, clarifying her standpoint on the matter. She highlights, first, the theoretical and conceptual perspective of someone who had devoted decades to the study of disability. Second, she underscores the "practical" perspective, insofar as she herself is a person with a disability (Amaral, 1998). By emphasizing her standpoint, the author is not restricting the right to speak about disability to those who experience it, but rather reinforcing the necessity for science to take into account epistemologies grounded in the perspectives of groups historically treated as objects of study on disability, yet rarely recognized as subjects.

Within the field of Disability Studies, among the groups once regarded merely as objects, autistic individuals have increasingly emerged as researchers of their own condition. Given the centrality of social relations to inclusion, most of these researchers share the perspective of neurodiversity and of the social model of disability, in opposition to a strictly biomedical view of Autism Spectrum Disorder (ASD) or autism (Araujo; Silva; Zanon, 2023; Wuo; Yaedu; Wayszceyk, 2019). The biomedical approach, centered on pathological aspects, analyzes autism solely through diagnostic criteria, as established in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the American Psychiatric Association – APA (2014), or in the International Classification of Diseases (ICD).

Researchers aligned with the neurodiversity paradigm acknowledge the importance of medical criteria in defining autism, Attention Deficit Hyperactivity Disorder (ADHD), and dyslexia, particularly in light of existing public policies and the choices of therapeutic, medical, and pedagogical support directed toward neurodivergent individuals. However, they caution against excessive medicalization and the restriction of behaviors, which have led to rejection and psychological distress by placing the blame for "failure" on the subjects themselves. For instance, international studies suggest that autistic adults tend to show a higher prevalence of conditions such as anxiety, mood disorders (depression), gastrointestinal disturbances, and social phobias, among others, often arising as a consequence of lifelong interactions (Forde; Bonilla; Mannion; Coyne; Haverty; Leader, 2022).

In Brazil, over the past fifteen years, we have also witnessed a period in which the voices of autistic individuals have gained greater visibility. Previously, representation was mediated through family members, teachers, or professionals involved: the National Policy for the Protection of the Rights of Persons with

Autism Spectrum Disorder – Law No. 12,764, of December 27, 2012 (Brasil, 2012) – is known as the Berenice Piana Law, in recognition of the efforts of the activist and mother of an autistic individual.

Currently, thanks to social media, the press, and inclusive policies, we have access to the experiences of diverse autistic individuals – children, adolescents, and adults – who share their daily lives and perspectives. Social perceptions of autism have also been reshaped by changes in diagnostic criteria and inclusive educational policies. Teachers in Basic Education, as well as researchers in the field, can no longer overlook these subjects. Within this context, I present the results of a study aimed at analyzing the protagonism of autistic students in academic research on autism and Basic Education.

This rationale can be extended to inclusive policies directed at autistic individuals and persons with disabilities within the Brazilian education system, such as: the Law of Guidelines and Bases of National Education (LDB) – Law No. 9,394, of December 20, 1996 (Brasil, 1996); the National Policy for Special Education in the Perspective of Inclusive Education (PNEEPEI) (Brazil, 2008), which, in reaffirming the LDB, brought regular education closer to students with disabilities; the previously mentioned National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder – Law No. 12,764/2012 (Brasil, 2012); and the Statute of the Person with Disabilities – Law No. 13,146, of July 6, 2015 (Brasil, 2015). With these policies transforming the school environment and introducing the "other" into the educational world, we must ask whether this "other" has been regarded as a research subject rather than merely as an object.

As Amaral (1998) does, I take the liberty of using the first person to make explicit my dual standpoint. I have worked with autistic students both as a teacher in Basic Education and in Higher Education, developing research and outreach projects; additionally, I am a Black autistic man. In this work, I prefer the terms "autistic person" or "autistic student" over the expressions "person with autism" or "student with autism". Autistic activists, guided by the social model of disability, advocate for the use of "autistic person" as a way to denote a characteristic of the individual and to challenge the pejorative use of the term, which is associated with the biomedical model of disability and reduces autism to a condition that the person merely possesses.

In the first part of this study, I discuss review studies on the inclusion of autistic students in Basic Education as a way to characterize the field of research and lay the groundwork for the investigation. Next, I outline the methodological aspects employed in this study. Finally, I present the results and discussion, engaging with both the literature reviewed and current legislation. In the concluding remarks, I synthesize the main findings of the research in dialogue with the contemporary context.

Review studies on the inclusion of autistic students in Basic Education

With the aim of contributing to and engaging in dialogue with this field of research, we synthesize here literature review studies on academic production concerning the inclusion of autistic students in Brazilian Basic Education, approached from different perspectives.

The study by Vasques (2009), grounded in Psychoanalysis, analyzed 200 theses and dissertations published between 1978 and 2006, based on searches conducted in the Capes Portal and virtual libraries of theses and dissertations. Most of the works identified were in the field of Psychology, followed by Education and Medicine. According to Vasques (2009), the number of publications increased from 2001 onwards, although, unfortunately, the article does not provide quantitative data to support this claim. Within the educational field, of the 43 works examined, the majority critically addressed the medical diagnosis, exploring its limitations through themes such as teaching and learning processes, family relations, teacher education, and the possibilities of inclusive education.

Teaching and learning processes, as well as the possibilities of inclusive education, were the focus of the investigation conducted by Nunes, Azevedo, Schmidt (2013). The authors analyzed 28 works (articles, theses, and dissertations) on the schooling of autistic students in mainstream classrooms, published between 2008 and 2012. The presence of autistic students in regular education increased significantly, driven by the paradigm of inclusion. The studies analyzed highlighted teachers' insecurities regarding inclusion, and despite the discourse of inclusion, pedagogical practices offered little support for students' learning. On the other hand, the articles pointed to solutions for learning, such as the collaboration of classroom aides with appropriate training, the use of various technological resources, curriculum adaptations, and multidisciplinary teams.

Ensuring the learning of content is also part of the discussions on access to the curriculum. Neves, Antonelli, Silva, Capellini (2014) conducted a literature review on academic production concerning the school inclusion of autistic students and curricular aspects. Grounded in historical-critical pedagogy, they defend the social role of the school in mediating knowledge and argue that such mediation has taken place to the detriment of inclusive education for autistic students. The study encompassed theses and dissertations published in the Digital Library of Theses and Dissertations between 1987 and 2011, totaling 51 works. The most frequent theme in the sample was the interaction of autistic students with the school community (teachers, peers, etc.), accounting for 25.49%; next, 21.57% analyzed curricular aspects, mostly case studies, revealing a lack of large-scale investigations on curricular strategies directed at autistic students. Furthermore, research on curricular adaptations focused primarily on modifications in teachers' pedagogical practices (e.g., the use of distinct teaching resources), without necessarily adapting the curriculum itself, which is a possibility foreseen in educational policies. The authors also connect curricular adaptations in school settings (focused more on didactic adjustments) to the third most frequent category, pedagogical practices (13.73%). This indicates a concern in academic production with "what to do" to ensure the learning of autistic students, almost as if expecting an instruction manual or a medical prescription.

Teachers' concerns about "what to do?" when faced with students in inclusive education, particularly autistic students, may indicate the influence of the medical discourse within the school environment. Rodrigues and Angelucci (2018) investigated studies on the schooling of autistic students in regular schools using online databases. Among articles, theses, and dissertations, they selected 52 works published between 2002 and 2015. According to the authors, the existence of a medical diagnosis as a criterion for defining the target population of special education constitutes an inevitable contradiction for education. The studies analyzed reveal: limited discussion of the school's social role, alongside an emphasis on the therapeutic aspect of learning, especially in works with a psychoanalytic orientation; a predominance of universal symptom descriptions based on diagnostic manuals, without reflection on the constitution of the subjects, even in works grounded in interactionist perspectives, such as those from historical-cultural psychology; and the assumption that teachers need a medical understanding of ASD to act effectively, resulting in a school that claims to adopt the paradigm of inclusion but is, in practice, closer to the paradigm of integration of autistic individuals, oriented toward rehabilitation (Rodrigues; Angelucci, 2018).

The biomedical discourse on ASD was also the subject of study by Wuo (2019) in a literature review of theses and dissertations published by graduate programs in the South and Southeast regions of Brazil, focusing on the education of autistic individuals between 2008 and 2016. According to the results, most of the approaches to autism in the 136 works selected were guided by a biomedical perspective (92 of the studies were in the health field), employing qualitative approaches, but noting the emerging critical recognition of the educational and cultural contexts of the subjects. Nonetheless, according to the author:

> In most of the studies, there is a specific section dedicated to explaining autism, which includes discourse based on the etiological explanations from official manuals, particularly the Diagnostic and Statistical Manual of Mental Disorders (DSM), explanations specific to the research field (education, psychology, speech-language pathology, psychopedagogy), and, in some cases, a discussion of the social aspects related to autism, including prejudice, discrimination, and other social barriers that limit the full development of individuals with ASD. From the biomedical model perspective, autism is presented through a discourse focused on the impairments resulting from the individual's psychological condition (Wuo, 2019, p. 219).

The danger of adopting a perspective narrowly focused on the biomedical aspect is the transformation of the school environment into a therapeutic setting (Rodrigues; Angelucci, 2018). Wuo (2019) highlights an example of this transformation of the school environment into a deficiency-focused therapeutic setting when the guiding questions of studies are framed with expressions such as "what are the main difficulties of teachers?" and "what are the greatest problems of students?", contradicting the ideals expressed in inclusive legislation.

The biomedical discourse will likely lose influence with the emergence of investigations in the educational field involving autistic students, rather than focusing solely on them. Melo, Lima, Barboza Netto, and Fernandes (2023), in a literature review of 22 articles containing interviews on autism within the fields of Education, Psychology, Medicine, and Nursing between 2008 and 2021, identified the main themes analyzed as: the social impact of the diagnosis (family and school); concerns regarding teacher training and learning; family relationships and support networks, particularly for mothers of autistic children. Although not explored by the authors in the article, according to the list of studies analyzed, their titles, and keywords, most research involved interviews with family members (mainly mothers), 14, followed by teachers, 4. Interviews with autistic individuals were present in 4 articles.

In summary, the studies indicate an increase in publications on autism and inclusive education over the past 15 years (Vasques, 2009), particularly following the approval of the National Policy for Special Education in the Perspective of Inclusive Education (2008) (Nunes; Azevedo; Schmidt, 2013; Neves; Antonelli; Silva; Capellini, 2014). This growth in publications should also consider changes in ASD diagnostic criteria, the increased enrollment of autistic students in regular schools and other settings (Wuo, 2019). Despite the discourse of inclusion being part of teachers' rhetoric, it remains distant from the reality of most autistic students (Nunes; Azevedo; Schmidt, 2013; Neves; Antonelli; Silva; Capellini, 2014). Inclusion has generally occurred only in terms of socialization of autistic students with peers at school, but not in terms of content learning (Neves; Antonelli; Silva; Capellini, 2014), with few studies focusing on what autistic students have to say about themselves, as indicated by the data from Melo, Lima, Barboza Netto, Fernandes (2023). Thus, the school distances itself from its primary social function, the mediation of all students' access to scientifically and historically constructed knowledge, while simultaneously assuming a biomedical or therapeutic character (Rodrigues; Angelucci, 2018; Wuo, 2019).

Research Methodology

We conducted a survey in online article databases, including the Periódicos Online de Educação (Edubase) and the Scientific Electronic Library Online (SciELO), between October and December 2024. For the investigation, we used the following descriptors:

- autismo OR transtorno do espectro autista AND escola;
- autismo OR transtorno do espectro autista AND educação;
- autismo OR transtorno do espectro autista AND educação infantil;
- autismo OR transtorno do espectro autista AND ensino fundamental;
- autismo OR transtorno do espectro autista AND ensino médio.

Reflecting on the research available in these databases, which are easily accessible to the academic public, contributes to an overview of the knowledge field on the topic. As inclusion criteria for the sample, we considered articles in Portuguese that presented research or reflections focused on institutionalized Basic Education. Articles in other languages, on Higher Education, or studies in educational contexts outside formal school settings were not included.

Content analysis procedures were adopted, following Bardin (2016), encompassing the stages of pre-analysis, material exploration, and data interpretation. Content analysis constitutes a set of tools aimed at analyzing symbolic constructions, serving as a starting point for inferences derived from the collected data. This type of analysis typically employs objective methods, such as frequency calculations, understood as methods whose results can be shared by different researchers (Bardin, 2016). Based on the descriptors and inclusion/exclusion criteria, during the pre-analysis stage, we selected potential articles for the sample through an initial reading of titles, abstracts, and definition of the focus of analysis. Next, full readings of the articles were conducted, disregarding repetitions. A total of 57 articles were selected for the sample. In the material exploration stage, categories were developed from the text readings. This categorization structures the content into units of analysis that allow interpretation. The categories created were: type of article; stage of Basic Education; concept of autism; and participants. Finally, we conducted the processing of results and interpretations, extracting patterns and relationships, and comparing them with the existing literature in the field.

The category "type of article" was developed to organize the articles according to the methodologies employed: field research; literature review studies; documentary research; theoretical reflections; construction and evaluation of research instruments; test applications; experience reports; comparative studies. The category "stage of Basic Education" was created to organize the articles according to the educational stage that was the focus of the study: Early Childhood Education; Early Childhood and Elementary Education; Elementary Education; High School; Indeterminate. Inspired by Wuo (2019), the category "concept of autism" was constructed to analyze the articles from two perspectives: research based on the biomedical model of disability and research based on the social model of disability. The category "participants" was developed to classify field research according to the participants: students; teachers; students and teachers; family members and teachers; students, teachers, and family members.

Furthermore, in the analysis of the "participants" category, we examined the protagonism of autistic students based on two criteria: 1) field research with the protagonism of autistic subjects (i.e., the research interacts directly with these subjects, listening to their different forms of expression, considering their experiences and perspectives on the school context); and 2) field research without the protagonism of autistic subjects (i.e., in the research, autistic individuals are the object of discourse and analysis by others, whether family members, classmates, teachers, or other school professionals, without the opportunity to speak for themselves).

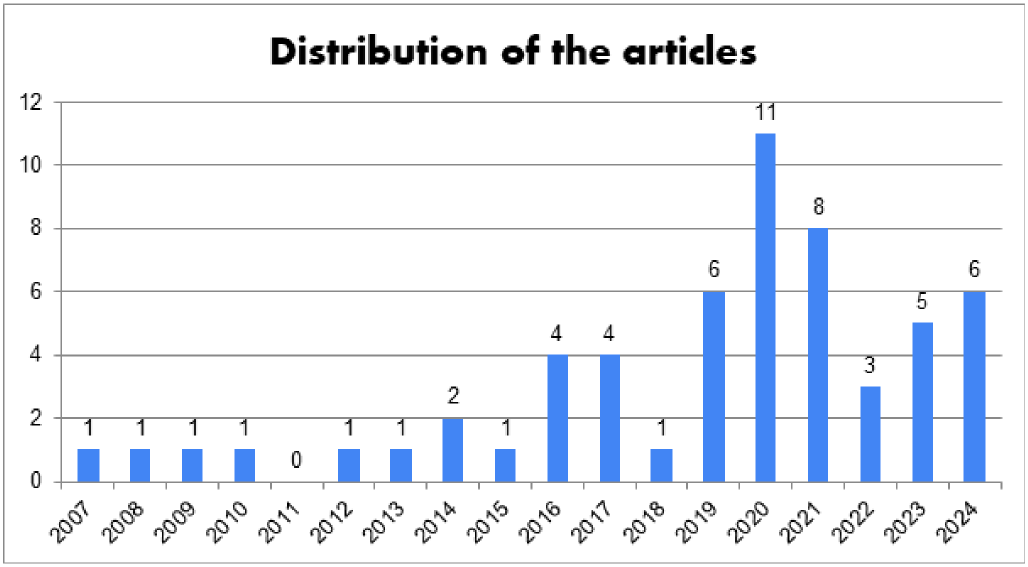
Results and Discussion

This section presents the results of the analysis of the 57 selected articles, organized into five categories: year of publication, type of article, stage of Basic Education, concept of autism, and participants. The discussion of the data is conducted in dialogue with the reviewed literature and the current legal framework, aiming to highlight trends, gaps, and contradictions in the academic production on autism and Basic Education.

Year of Publication

The following graph (Figure 1) presents the distribution of the 57 articles according to their year of publication.

Figure 1 – Distribution of the 57 articles by year of publication



Source: Author's own elaboration.

The earliest article in the sample was published in 2007, and the most recent in 2024. A clear trend of increasing publications on autism and school education can be observed over the past ten years. We attribute this growth, as do authors cited in the literature review (Nunes; Azevedo; Schmidt, 2013; Neves; Antonelli; Silva; Capellini, 2014; Rodrigues; Angelucci, 2018; Wuo, 2019), to the National Policy on Special Education in the Perspective of Inclusive Education (2008), which facilitated the entry of a greater number of autistic students into regular education, and to changes in the diagnostic criteria for autism introduced in the DSM-5 (2013). Examination of the authorship of the articles revealed that four studies were authored by the same researchers, reflecting the formation of research groups on autism that involve university professors, master's, and doctoral students.

Over this 18-year period, the year with the highest number of publications was 2020 (11 articles), deviating from the overall trend. It might be tempting to associate this increase with the social isolation resulting from the COVID-19 pandemic, as some misinformation (unfortunately even circulated by educators) suggests by attributing the "cause" of rising autism cases to "lack of social interaction among children" or "vaccines". To clarify, we examined the submission dates of the 11 articles published in 2020. Of these, 2 were submitted in 2018, 6 in 2019 (of which 2 were part of the same dossier), and 3 in 2020 (1 in February, 1 in May, and 1 in June). Therefore, there is no evidence of a relationship between the COVID-19 pandemic and the increase in academic research on autism and school education, just as there is no relationship between the increase in autism cases and the COVID-19 pandemic.

Type of Article

In the discussion of the results for the category "type of article" (Table 1), we cite articles that we consider relevant to illustrate the subcategories.

Table 1 – Type of Article

Type of article	Frequency	Percentage
Field research	33	57,9
Literature review	9	15,7
Documentary study	5	8,8
Theoretical study	4	7
Instrumental study	2	3,5
Tests	2	3,5
Experience report	1	1,8
Comparative study	1	1,8
Total	57	100

Source: Author's own elaboration.

Field research accounted for more than half of the articles identified (57.9% of the sample) and was predominantly qualitative in nature, focusing primarily on case studies and ethnographic studies. The case studies aimed to understand the relationships between teachers and students in classroom settings, collecting data through video recordings, field journals, and direct interactions with participants. Research on teachers' perceptions of autism (and of autistic students) employed questionnaires and interviews as data collection instruments.

As noted by Neves, Antonelli, Silva, Capellini (2014), there is an absence of large-scale field research involving autistic students in educational contexts, which poses challenges for the evaluation of public policies.

Literature review studies were the second most common type, accounting for 15.7% of the sample. In our own literature review, we have already synthesized the studies identified and refer to them in the subsequent analyses.

Documentary research accounted for 8.8% of the sample and involved analyses of public policy legislation. For example, one study examined the teaching plan of a municipality in the interior of Goiás (Montel; Souza; Lemos, 2021), while another conducted a documentary analysis of the various terminologies used in Brazilian public policies directed at ASD (Felisbino; Graff, 2024).

Overall, articles classified as theoretical reflections accounted for 7% of the sample and contrasted biomedical paradigms with approaches aligned with the social model of disability. For instance, in defense of the social model of disability, Pimenta (2019), drawing on psychoanalysis, reflects on inclusive school legislation, which effectively considers autistic students as individuals with disabilities. According to the author, framing ASD as a disability based on the characteristics outlined in medical manuals carries the risk of overlooking the unique particularities of each autistic individual.

One theoretical article did not challenge the biomedical model, instead defending evidence-based practices in the teaching methods used for autistic students in special education (Nunes; Schmidt, 2019). In their discussion, the authors argue that evidence-based practices are not implemented in classrooms because the teaching methodologies learned in universities are determined by ideological rather than scientific factors (the authors do not specify which ideologies). However, in addition to presenting a biomedical view of autism without critiquing it, the article overlooks that even the adoption of scientifically effective practices depends on ideological choices, approaching an idealized notion of scientific neutrality.

Articles on the construction and evaluation of instruments (3.5% of the sample) present tools designed to support teachers in educational contexts. For example, the study by Soares and Nunes (2020) on the Mediated Learning Scale aimed to assess teachers' mediation with autistic children. This article was published in a thematic dossier on pedagogical and social aspects of autism.

In summary, considering the type of article, a majority were field research studies, primarily case studies. The second most common category, literature reviews, although less frequent, indicates a growth in publications in the field. Documentary research is relevant because it supports policy decisions regarding the rights of autistic students in education, yet it needs to be integrated with large-scale field studies. Theoretical reflections typically questioned the limitations of diagnoses based solely on biomedical factors, as well as the impact of medical reports in classroom settings. Articles on instrument construction or evaluation highlight current concerns regarding pedagogical practices for autistic children and the renewed role of educators in decision-making about how to act.

Other categories. In the "tests" category, the articles reported autistic students' performance on academic achievement tests, including one on reading and text comprehension and another covering reading, writing, and arithmetic. The article presenting an experience report described the inclusion process of an autistic student in the regular education system. The comparative study examined social competence in two early childhood students, one autistic and one neurotypical, considering the classroom and playground as contexts for interaction.

Stage of Basic Education

The stage of Basic Education most represented in the sample was Elementary School, with 21 articles (36.8% of the total). Research at this educational level frequently consists of case studies focusing on teachers' perceptions. In studies within the field of Mathematics, concerns regarding inclusion beyond socialization were highlighted by Souza and Silva (2019) in a study that employed digital technologies to teach mathematical operations to autistic students.

Next, articles without a specified educational stage (undefined) accounted for 19 (33.3%). This category included literature reviews, document analyses, or theoretical reflections on the inclusion of autistic students in Basic Education.

Research in Early Childhood Education comprised 11 articles (19.3%), mostly case studies centered on teachers' perceptions or student monitoring. Additionally, three studies (5.3%) involved case studies with teachers working across both Early Childhood Education and Elementary School.

Three studies were identified about the High School (5.3%). Notably, the work of Vasconcellos, Rahme, and Gonçalves (2020) in Integrated High School was one of the few studies presenting the perspective of autistic students regarding inclusion, based on interviews.

Concept of Autism

The biomedical model of autism, based on the definitions provided in the DSM-5 and the ICD, prevailed in the sample, appearing in 42 articles (73.7% of the total). As observed by Wuo (2019), some studies presented the DSM-5 definition in the very first paragraph, almost as a formal authorization to address the topic. The most extreme instance of biomedical discourse was a 2017 article that described the observed students according to the ICD-10 code in each medical report.

The social model of disability was advocated in 13 articles (22.8%). In these works, authors sometimes presented the medical manuals' criteria only to subsequently highlight their limitations, emphasizing contextual and historical aspects, denouncing the stigmatizing use of medical reports, and stressing the inclusion of autistic individuals in society. When relating these articles to their year of publication, it is observed that, of the 13 adopting the social model, 12 were published in the last six years of the sample (2019–2024), indicating a growing trend in studies with this focus (also noted by Wuo, 2019). In two articles (3.5%), no definition of autism was provided.

Regarding studies aligned with the social model of disability, four articles incorporated psychoanalytic concepts in their critique of the biomedical model. Although these perspectives were closer to the social model than the biomedical view, the psychoanalytic approaches still considered autistic individuals solely from a therapeutic analysis standpoint—an aspect also noted by Rodrigues and Angelucci (2018). In this sense, these works represent more a substitution of the biomedical model with a biopsychological model, which remains distant from the typical teaching and learning contexts of Basic Education.

A reading of the texts also revealed terminological changes in references to autistic individuals and persons with disabilities. Studies published prior to 2015, for example, used terms such as "childhood autism" and "person with a disability". From 2015 onward, only two articles (in 2021 and 2022) used terms like "disorder carrier" and "persons with special needs". This shift can be attributed to discussions on inclusion and the advocacy of disability rights. Only one article, published in 2017, contained a serious conceptual error by claiming the existence of research linking autism to vaccines, without citing any source and without acknowledging that such speculation had been refuted since the early 2010s.

Participants

The aim of our analysis of the 38 field studies was to examine: 1) who the participants of these studies are, and 2) the potential for protagonism among autistic individuals.

Among the 38 field studies, 14 (36.8%) were conducted with autistic students (e.g., interviews with high school students; monitoring a student throughout the school year), which is the same number as studies conducted with teachers (14 = 36.8%), mostly focused on teachers' perceptions of autism. Studies in which teachers and students participated jointly (e.g., through classroom interactions) totaled 7 (18.4%). Students, teachers, and family members were involved in two studies (5.3%), while family members and teachers participated in only one study (2.7%).

Considering only studies with autistic participants, there is a total of 23 studies. However, when examining the protagonism of autistic students in these studies, only five of them treated autistic individuals as active subjects of the research, providing space for their diverse forms of expression and their experiences and perspectives on the school contexto.

It can be asserted that the protagonism of autistic students in research is directly related to the methodologies employed. In most cases, the researchers acted as participant-researchers. This was the case in the studies by Souza and Silva (2019), involving two autistic elementary school students (one boy and one girl) on digital technologies and mathematics learning; Francês and Mesquita (2021), focusing on the perception of time and space of one autistic child (boy) in Early Childhood Education; and Moura and Camargo (2021), with six autistic students (four boys and two girls) on science concepts. Freitas (2021) also acted as a participant-researcher with Bolivian children suspected of ASD, although the article did not report the number of children or their gender. The exception to the participant-researcher methodology was the study by Vasconcellos, Rahme, and Gonçalves (2020), which involved an interview with one high school student (male).

The characterization of the gender of autistic protagonists proved to be relevant in the analyzed studies. Beyond gender, it is argued that research should characterize participants using social markers such as race and social class, as stereotypical views of autistic individuals still persist in everyday school contexts. With the exception of Freitas (2021), who examined how immigrant children from low-income Bolivian families have experienced stigmatization in school, the studies in the sample did not employ markers beyond gender. An intersectional analysis of the articles was not part of the objectives of this investigation; however, considering that social markers such as gender, race, and class affect access to public policies in Brazil, this is suggested as a topic for further research.

The limited number of studies conducted with autistic individuals (rather than merely about them) indicates that there is little space in academic research for the voices of this group. Given the educational policies aimed at students with disabilities, the scarcity of studies involving autistic individuals may result in shortcomings in the evaluation of existing inclusive public policies for this population.

The absence of protagonism among autistic students was observed both in the majority of field studies in which they participated and—especially—in those in which they were not direct participants. In these investigations, whether involving teachers or family members, autistic students were treated as objects of analysis and reflection, interpreted through the perspectives of others.

The number of field studies focusing exclusively on teachers (14) corresponds to the number of articles offering theoretical reflections on teaching practices. Considering the concerns addressed in these articles, there appears to be a prevailing question among educators regarding how to accommodate autistic students in regular classrooms. The studies consistently portrayed teachers as methodologically unprepared to work with autistic students, despite their efforts and good intentions. While the methodological concern is understandable, its emphasis tends to reduce teaching practice to a purely technical act.

Field research involving teachers provides important data. However, it does not delve into how these professionals reflect on their own practices nor how these practices are actually implemented. For instance, all articles addressing inclusion from the teachers' perspective explicitly state that participants support inclusion and claim to act accordingly. Yet, no study goes beyond this politically correct discourse: which teacher, in recent decades, would admit to being against inclusion or doing nothing about it?

Moreover, when teachers report feeling unprepared, and considering the biomedical discourse, one can problematize the type of methodology they expect to learn in order to work with autistic students. Is it a methodology specifically aimed at educating, or a methodology specifically aimed at caring for autistic individuals? Basic Education, in a sense, navigates between these two approaches, and in the case of autism, the studies reviewed are more concerned with care than with education, as the biomedical report seems sufficient to render education impossible. As Felisbino and Graff (2024) argue, the adoption of the biomedical discourse may generate blame towards the individuals; after all, if they do not learn, it is due to the reasons outlined in the report.

Still considering the distinction between "educating" and "caring", one can cite the study by Gomes and Mendes (2010) on the perspectives of teachers from the Belo Horizonte school system regarding the schooling of autistic students. It was the only study in the sample that sought to understand, beyond socialization, how teachers assessed the learning of content by autistic students.

Even though the 33 teachers in the sample indicated positive aspects, such as the good school attendance of autistic students, they also highlighted concerns regarding the limited learning of content. In this sense, they were concerned both with caring for and educating autistic students.

Final considerations

Based on the objective of this study (to analyze the protagonism of autistic students in academic research on autism and Primary and Secondary Education) 57 articles available in the Edubase and SciELO databases were examined. The articles were organized according to publication year, article type, educational stage, concept of autism, and the protagonism of autistic individuals.

The analysis shows that, although academic interest in autism and Primary and Secondary Education has increased significantly since the second half of the 2010s, the protagonism of autistic students in research remains limited. These findings highlight the gap between the discourse of inclusion and the practice of educational research, reinforcing the need for epistemological shifts that recognize autistic individuals as active agents in the construction of knowledge about their own schooling.

Most of the studies were field-based, particularly case studies, confirming trends noted in earlier research. Articles centered on theoretical reflections and the evaluation of instruments reveal a parallel tendency: a questioning of the biomedical model and an effort to build an epistemological foundation specific to education. Meanwhile, isolated documentary studies and legislative analyses suggest that policy monitoring still lacks integration with broader empirical investigations, limiting the effectiveness of inclusive practices. Elementary Education was the most frequently examined stage, reflecting a predominant concern with "caring for" autistic students rather than "educating" them. In practice, despite inclusive discourse, autistic students often remain excluded within the classroom.

The dominance of the biomedical model of disability in the studies confirms an approach that treats disability primarily as an object of analysis, while the social model of disability (though increasingly presente) still faces obstacles to becoming consolidated. Broadening the protagonism of autistic students therefore requires incorporating their voices into the epistemological foundations of the field. This means shifting from research about autistic people to research conducted with and by them, as an essential condition for the genuine transformation of inclusive practices.

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