ABSTRACT: The academic trajectory can be complex for atypical mothers due to the accessibility barriers faced by students with Special Educational Needs enrolled in regular Brazilian schools, despite the legal provisions that guarantee this right. This article, originated from the Master's thesis in Education completed in 2017, presents narratives from five mothers of children with Autism Spectrum Disorder about their experiences with their children in Early Childhood Education in a regular school, as well as their expectations regarding the future. The methodological procedure was qualitative anchored in the principles of (Auto)biographical research, having in the narrative interviews its source of data production. The results showed the perception of these women about the importance of the school environment for the social and pedagogical development of children, but pointed to the need for a review of the pedagogical model and teacher training so that the process of school inclusion can actually take place.


RESUMO: A trajetória acadêmica pode ser complexa para mães atípicas devido às barreiras de acessibilidade enfrentadas por alunos com Necessidades Educacionais Especiais matriculados em escolas regulares brasileiras, apesar dos dispositivos legais que garantem esse direito. Este artigo, originado da dissertação de mestrado em Educação concluído em 2017, apresenta narrativas de cinco mães de crianças com o Transtorno do Espectro Autista a respeito de suas experiências com os filhos na Educação Infantil em escola regular, bem como suas expectativas com relação ao futuro. O procedimento metodológico foi qualitativo ancorado nos princípios da pesquisa (Auto)biográfica, tendo nas entrevistas narrativas sua fonte de produção de dados. Os resultados evidenciaram a percepção dessas mulheres acerca da importância do ambiente escolar para o desenvolvimento social e pedagógico das crianças, mas apontaram para a necessidade de uma revisão do modelo pedagógico e de formação de professores para que o processo de inclusão escolar possa acontecer de fato.

RESUMEN: La trayectoria académica puede ser compleja para las madres atípicas debido a las barreras de accesibilidad que enfrentan los alumnos con Necesidades Educativas Especiales matriculados en escuelas regulares brasileñas, a pesar de las disposiciones legales que garantizan este derecho. Este artículo, originado a partir de la tesis de Maestría en Educación concluida en 2017, presenta narrativas de cinco madres de niños con Trastorno del Espectro Autista sobre experiencias en Educación Infantil en escuela regular y expectativas con respecto al futuro. La metodología fue cualitativa anclada en los principios de la investigación (Auto)biográfica, teniendo en las entrevistas, narrativas su fuente de producción de datos. Los resultados mostraron la percepción de estas mujeres sobre la importancia del ambiente escolar para el desarrollo social y pedagógico de sus niños, pero señalaron la necesidad de una revisión del modelo pedagógico y de la formación docente para que el proceso de inclusión escolar pueda concretarse.


Introduction

Inclusion is a complex theme, from which numerous interdisciplinary discussions are established. Talking about inclusion implies dealing with differences and otherness, reaffirming the guarantee of all to enjoy their rights as citizens and legitimately occupy their place in society (SASSAKI, 1999). From the point of view of legislation, Brazil has sought, in recent decades, to align itself with the global movement initiated in 1990 in the direction of Inclusive Education. Currently, based on the Federal Constitution (BRASIL, 1988), all Brazilian children and adolescents have guaranteed the right to attend regular school, including those who present air in any Special Educational Needs (NEEs)³, among which are the students diagnosed with autism spectrum disorder (ASD).

It should be remembered, however, that entering school introduces the child into a social context in which they are asked to develop different skills, and new expectations about their behavior and performance are established. If this causes fear and anguish in mothers in general, in those whose children are autistic, such emotions are enhanced, since these children may face some accessibility barriers that hinder their neurodevelopment considered atypical, with emphasis on the areas of learning and social relations. More than neurotypical children, autistic

---

³ Author's note: The term NEE is now used in the educational context to designate students who have some disability or learning difficulties and which raises interpretation.
children may need support at various levels to be included in a social environment, such as school, and with pedagogical use. The attribution of mothers becomes, then, fundamental, because it is up to them to act many times as mediators of children, considering their different levels of communication skills and social interaction. We are led to believe that these atypical mothers live challenging experiences that deserve to be narrated and shared in order to reflect on the processes of inclusion of children with ASD in regular schools since Early Childhood Education. Therefore, we intend, in this text, to present some of the narratives of the mothers who collaborated with the research so that, with such experiences, we can contribute to the continuous construction of a school of work as an inclusive space of learning and coexistence for all.

We start from the assumption that narrating a story is a way of organizing and attributing meaning to lived experiences (BRUNER, 2002), because it favors, to the narrator, an opportunity to temporally order the events that permeate their existence and to build meanings for them. When telling a story, the subject plots subjective, intersubjective and cultural plans, offering a precious material about what is happening in their lives and those who are close to them.

In order to achieve the proposed objective, we started by addressing the legislation that defines the inclusion of children with ASD in Brazilian schools, we highlight some studies that present possible etiologies of ASD and, then, include the narratives of mothers, anchored in lived experiences that intersect and get rich through analysis and dialogue with studies on the subject. The final considerations remain open and are organized in order to reflect on the research findings.

---

4 Author's note: atypical motherhood is a concept that has been used to differentiate, in general, the motherhood of women, whose son or daughter has neurodevelopment different from that considered typical and within a standard and therefore are commend by a differentiated experience of motherhood.

5 Text based on research data developed by Tambara (2017) in her master's degree in education with CAPES scholarship under the guidance of Professor. Ecleide Cunico Furlanetto. The text is part of the project: "Narratives, education, health: epistemology and methods of (auto)biographical research with children". Research project funded by MICT-CNPq (Call No. 06/2019, process no. 307063/2019-4), coordinated by Professor. Dr. Maria da Conceição Passeggi - UFRN. It is an international project that brings together research groups in Brazil and in different countries, with the objective of putting into dialogue the meanings constructed, narratively, by children, their families and teachers on health and education.
The legal aspects of inclusion in Brazil

From the Universal Declaration of Human Rights, adopted and proclaimed by United Nations General Assembly Resolution 217-A (III) on December 10, 1948, guidelines on the Public Policies of member countries, including Brazil, as a member of the UN were defined. In turn, with the promulgation of the Federal Constitution (BRASIL, 1988), elementary school became compulsory schooling for all Brazilian children and adolescents, mandatory extended, from 2009 (Amendment 59), to the age group of 4 to 17 years of age, including, therefore, from the final years of Early Childhood Education to High School (CF, art. 208, item I). In addition, the child with any SEN has achieved the right to receive complementary specialized care, preferably within the regular school (CF, art. 208, item III). Another important step was taken in 1990 with the approval of the Statute of the Child and Adolescent (BRASIL, 1990) which, in turn, reiterated what was recommended in the Constitution.

Overall, the Jomtien Declaration (1990) and the Salamanca Declaration (1994) were two important milestones for the consolidation of Inclusive Education. Brazil, a signatory of both documents, has committed to establish policies aimed at promoting education for all students, with and/or without disabilities. Specifically, the Law on Guidelines and Bases of National Education (BRASIL, 1996) and the Guatemalan Convention of 2001 reinforced inclusion prohibiting any kind of differentiation, exclusion or restriction based on any disability presented by a citizen. In Brazil, therefore, the entry of a child with a child in regular school is a right guaranteed by law, as pointed out in chapter V of the Law of Guidelines and Bases of National Education (BRASIL, 1996), which deals with Special Education.

With regard to children with ASD, Law 12.764/2012 instituted the National Policy for the Protection of the Rights of Persons with ASD (BRASIL, 2012), taking into account the principles of the National Policy of Special Education in the Perspective of Inclusive Education (BRASIL, 2008a) and the purpose of the Convention on the Rights of Persons with Disabilities (BRASIL, 2008b). According to § 2. article 1.º, the person with ASD was considered a disabled person for all legal purposes and, from then on, the Brazilian State began to promote its access to regular school. Finally, following global trends related to the inclusion of people with disabilities, the Brazilian Law of Inclusion (Statute of Persons with Disabilities), Law 13.146/2015 (BRASIL, 2015) entered into force in 2016, affirming the autonomy and capacity of these citizens to perform acts of civil life on equal terms with others.

However, from the moment that the debates on inclusion gained strength in various areas of society, it was possible, more clearly, to identify the weaknesses both in relation to
compliance with the laws that seek to regiment procedures of action and the points in which the educational system needs to be focused on the promotion of improvements aimed at reducing, or if possible, the elimination of accessibility barriers in the various areas so that, in fact, Inclusive Education is effective. From the legal provision on barriers (art. 3 of Law 13146/2015) a classification of accessibility is proposed. In this sense, Sassaki (2020, p. 25) suggests the existence of seven distinct dimensions, namely: architectural, communicational, transport/mobility, programmatic, instrumental and natural. Considering, however, special education from the perspective of inclusive education, three dimensions deserve greater attention, without which one cannot talk about access of children with disabilities to school: the architectural, and communicational dimension. It is important to point out that such barriers can be found at various levels, from the subtest to the most explicit. All are, however, experienced by the Disabled Person and his family as a form of violence and oppression that generates disadvantage. However, the most subtle violence is the most difficult to combat.

**Autism Spectrum Disorder**

According to the Diagnostic and Statistical Manual of Mental Disorders, in its 5th edition - DSM 5 - (APA, 2014), autism spectrum disorder is a neurodevelopmental disorder and is characterized by a dyad composed of social and communication deficits and repetitive and restrictive behaviors. A recent study published in JAMA Pediatrics in 2022 revealed a prevalence of autism in the United States of 1 autistic per 30 children and adolescents between 3 and 17 years. The most current prevalence reported in December 2021 by the CDC Network (the U.S. government's Center for Disease Control and Prevention), considered one of the most relevant in the world, was 1 in 44.  

Some theories have sought to explain the etiology of primary harm in autism. Lamprey (2004) discriminated three phases. In the first, initially formulated by Leo Kanner in the 1940s, autism was defined as an affective contact disorder. Psychoanalysts such as Bruno Bettelheim, Margareth Mahler and Jacques Lacan reinforced this assumption. In the second phase, the perception prevailed that it constituted a developmental disorder that encompasses severe cognitive deficits, resulting in a brain dysfunction in which processes of attention, memory, sensitivity to stimuli and language are involved. The Theory of Mind was the most used to investigate cognitive aspects in autistic individuals, referring to the ability to take into account

---

the mental states of individuals in order to understand and predict behavior in social situations (BARON-COHEN, 1995; FRITH, 1996), necessary skill in almost all social situations. Other cognitive theories integrate this phase, among them, the Theory of Central Coherence (HAPPÉ, 1993), the Theory of Executive Dysfunction (HARRIS, 1994; OZONOFF et al., 1991) and language impairments (RUTTER, 1976). Finally, in the third phase, the so-called Developmental Approach addresses the impairment in the development of nonverbal communication and language, the difficulties of interaction and social understanding in people with ASD as a result of the innate inability to relate to people and to respond emotionally to others (HOBSON, 1989; MUNDY et al., 1993; STERN et al. 1977; TREVARTHEN, 1996).

Taking into account the characteristics of the condition, the work to be performed by the school and, specifically, by the teacher, depart from the pedagogical practice designed for neurotypical children, that is, those who do not have alterations in neurological development. A study conducted by Gomes and Mendes (2010) indicates that most students with ASD cannot learn by traditional methods, considering that 90% of these children do not follow the pedagogical contents developed in schools. Therefore, for the target audience of special education to have learning gains, environmental adequacy, adapted curriculum, diversified pedagogical strategies, implementation of an individualized educational program are necessary (ARANHA, 2003; BLANCO, 2004; FREITAS, 2006; MCLoughlin; LEWIS, 2001) and guarantee of access to Specialized Educational Care (ESA) as provided by Decree No. 6,571/2008 and Resolution No. 4 CNE/CEB of 2009.

**The meeting with mothers**

The study that originated this article was based on the principles of (auto)biographical research, a name that, according to Passeggi (2020), emerged in Brazil in 2004 on the occasion of the 1st International Congress of Research Autobiographical (CIPA). The use of parentheses to name this approach seeks to draw attention to the subjectivity received in the research that has biographical and autobiographical narratives as an object of investigation.

Narratives, while revealing individual experiences and can shed light on subjectivity, are also constitutive of specific socio-historical phenomena on which biographies are based (CRESWELL, 2014). We consider narratives, then, as representations or interpretations of the world and, therefore, not subject to proof, because they express the truth from a point of view in certain time and space. We chose as a procedure of data production the narrative interview
that, according to the guidelines of Jovchelovitch and Bauer (2002), is characterized as an unstructured tool that allows the focus of life stories crossed with social contexts.

Five mothers of autistic children living in municipalities belonging to Greater São Paulo participated in the study. The real names were kept confidential and we will adopt the fictional ones to refer to them and their children, all male, confirming research data that indicate a proportion of 1 girl for every 5 boys with ASD. Daniel, Julia’s son, and Gaius, Denise's son, studied in private regular schools. Guto, Carla's son, Rodrigo, Fabiana’s son, in schools of the Municipal Schools of Teaching of their cities. Dulce's son Gui, at the time of the research, was in a special school, but had attended two private regular schools previously. The age of the participants ranged from 35 to 45 years and the education of Incomplete Higher Education to graduate school. The professions were diverse: doctor, nurse, physiotherapist, pedagogue and housewife. Two of them were not inserted in the labor market and all were married during the period in which the research was conducted.

What mothers tell...

The careful analysis of the narratives of the interviewed mothers brought up some correlated themes that, in turn, gave rise to three axes of analysis listed below: the school adaptation phase; the importance of staying in regular school; and expectations about the future of their children in terms of life projects.

The adaptation stage

The entry into school and the adaptation period requires children, in general, the interaction with the pedagogical team and their peers, an important challenge, considering the characteristics of children with ASD and accessibility barriers, especially in their communicational and attitude dimensions, often present in the educational environment. In this phase, the differences between the development of children are presented, supported by the questions of language and social skills. It is evident the importance of finding a teacher who can, through the construction of the bond, but supported by good pedagogical intervention practices (GLAT; NOGUEIRA, 2003; PAPIM; ARAÚJO; PAIXÃO; SILVA, 2022), discover a way to communicate with the child and establish a bond of trust, promoting this adaptation. In partnership with the school, at this time, many families begin a long search to understand what is happening to their children.
It was horrible because every day I took my son to school. Every day he would cry and his teacher would say, "Calm down, Mom! He just cries to get off his mother. He looks great back in class!" And I thought at that time that he was going to develop some skills and even speech. Time went by and I didn't see it happen, I saw my son increasingly distressed and more distressed to go to school. In the meantime, we began to see that it wasn't just a matter of speech. We started investigating and we came to the diagnosis of autism (Fabiana).

She called me! The coordinator. It was terrible! She showed me a video of kids stacking toys. And she said, "Look, your son is like that." And I got it, I said, "Oh, my God in heaven!". She said it was just me passing the neurologist. She's the one who referred me to one, she was very good. Wow!! I thank God and her! She's been a lot of guidance to me. You clicked me. Because we, like it or not, say, "Oh, no! It's normal. It's going to pass!" (Carla).

This path permeated by experiences, often classified as terrible by mothers, leads them to a clinical investigation and, later, to confirm the diagnosis of ASD, which, for many children, only occurs when they enter school. A study by Meimes, Saldanha and Bosa (2015), which sought to investigate the beliefs and feelings of mothers of mothers of children with ASD, showed that the period that follows the diagnosis is marked by the predominance of the feeling of impotence, the fact that they do not know what the disorder is and how to act, triggering insecurities about achieving or not meeting your needs and demands. Smeha and Cezar (2011) point out that the confirmation of the diagnosis generates a feeling that involves the whole family, since this group is faced with the imperative of reorganizing itself through the realization that one of its members is autistic, which can often cause important changes in routine and life projects. New stories will be told and the lives of all family members will be affected, especially that of the mother, because it is she who is commonly more dedicated to caring for her children.

Because we say that our son is the most beautiful, is the smartest, that's what we expect when we are pregnant. When you see that the other kids are all on a path and your child is falling behind, that's hard and when, even more, the test gives autism! Wow, it's hard. I think if I could I'd move to another planet with Gaius around the time I got the diagnosis (Denise).

The children's school is fundamental in this process of detection and early intervention, when there is the perception of any indication of risk of development in some child in the group. The main objective of early intervention is to ensure that children with atypical development, or the risk of manifesting it, receive the necessary stimulations, enabling them to include family, school and social, as well as their personal autonomy.
The importance of staying in school

After the phase we call adaptation, which often involves diagnosis, comes an even greater challenge: staying in regular school with real pedagogical use, in addition to gains in socialization. For this to happen, it is essential that the entire school team is engaged in the construction of an inclusive environment, and the narratives of the participants highlight some obstacles that hinder its implementation. After diagnosis, some families request the presence of a specialized professional to accompany the child exclusively during the regular period of class. This work of pedagogical monitoring and mediation of social interactions can receive several denominations: therapeutical companion, a pedagogic companion, class auxiliar, inclusion companion, teacher of support.

There are questions in the academic circles about the presence of this professional with the argument that camouflages possible deficiencies of the school or prevents the gain of autonomy of the student (MANTOAN, 2003). However, studies point to its relevance when there was greater collaboration between educators from the regular school and the special school in simultaneous care and with a therapeutic companion or auxiliary teacher with adequate training and supervision (DIAS, 2017; HAAS et al., 2016; NUNES; AZEVEDO; SCHMIDT, 2013; PADILHA, 2013). Those who lived the experience of the presence of the companion highlights its importance for the permanence of the child in school, reporting, however, his commitment to convince the school to accept this professional.

[...] And then a "little feud" with the school began, because the principal already said: "Leave, each child has his time and has many things that are normal of age, keep running, keep jumping". [...] in the end... we went to talk to the principal of the school. My husband and I cry! Because it's desperate, Daniel likes school, he always likes it, he feels good there. If you think about switching schools... All right, but he already liked it there! And so, we thought: Because he's different, you have no right? Then the director was to give the answer, [...] finally, I covered by e-mail: "I count on your partnership, remembering that you need to be an exclusive person". [...] That day he called me and said, "You can bring the girl!" (Julia).

It is also worth remembering that, according to Law 12.764/2012, schools cannot refuse the enrollment of autistic students, establishing their right to study in regular schools, both in Basic Education and Vocational Education, and, if necessary, with the accompaniment of a specialized professional. Sanctions are also imposed on managers who deny enrollment to students with disabilities. For its part, Law 13.146/2015 guarantees more rights to people with disabilities and provides for punishments for discriminatory acts. Among the rights guaranteed
by the new law to meet this portion of the population is the offer of school support professionals, at no cost to families.

What we have found, however, is that instead of a specialized companion, schools end up offering a "caregiver". It is important to emphasize that not every autistic student will need a mediator, besides the teacher in the classroom, but the law provides for this right when it is verified their need. However, as the specificities on the subject are not clear in the legislation, the presence of the assistant class teacher or the exclusive teacher is often only achieved by means of a judicial injunction.

[...] There's an assistant and the teacher and the caregiver. Just for Guto, for example, to go to the bathroom, go to the mess hall. Eat, he eats alone. And brushing your teeth, just at home! The assistant does not help in the pedagogical part, sits next to it. It's just over there. So, it's too complicated! He's not a pedagogue. There's no guidance! (Carla).

[...] I knew that by law my son had the right and we started to argue and then came the Inclusion Team of the Secretariat until then I had never talked to them. And we hit it right in the face. I've had a lot of a talk with her. [...] I don't know if she's used to dealing with mothers who don't know the laws and the rights. She came talking about half a dozen laws and saying that my son was heeded because he had an assistant and that he had nothing to do with having one for each [...] And I told you That I knew the laws and rights of my children. Anyway, she [...] asked me for 40 days of experience with just one companion (Fabiana).

(referring to the room assistant)! In fact, today, she shares it with another boy with autism. But she's not in the living room. She's there for him, to help him at school. So, she helps in the bathroom, she helps to make the food plate, she helps to have more attention and concentration at the time of activities. Doing the lesson too, it helps, mediates between him and the classmates when he needs it. It helps in everything, so!! (Fabiana).

In addition to this impasse, the mothers, however, perceive the relevance of the work of the ESA, implemented through Resolution 47 of October 2, 2009, which establishes the operational guidelines for specialized educational care in basic education.

[...] He has the specialist teacher who goes to school once a week. And then she brings both activities to the group, which promotes socialization and his inclusion in the group, as well as individual activities to work, things he is in need of, like movement of tweezers to hold a pencil and a better pen. [...] Exercises to work increased attention and permanence in activities. She comes once a week. She brings adapted pedagogical material and gives guidance to the teacher and his assistant. In addition, she also gets in touch with the specialist aide teacher, who he goes to once a week. He stays an hour with an

---

7 AEE is the acronym for Specialized Educational Care. The ESA is a service provided for in law whose objective is to serve the target audience of Special Education, which are children with disabilities, autism spectrum disorder, high skills and gifted.
expert teacher alone, in a room of multimedia resources and finally a lot of adapted material, pedagogical at last. And there she works, continues the work of the expert teacher to develop skills that he should already have at the age to achieve evolution within the school (Fabiana).

The difficulties presented by both public and private schools with regard to the inclusion of autistic children gain importance in the mothers' narratives, especially when referring to the performance of teachers and the entire school team in general.

[...] She's already 30 years old, but everything for her was new. So, it's hard!!! I think it's hard for everyone! Only people need to accept inclusion, I think it comes from within their own hearts! People need to accept and they need to put out what they know to deal with that child! And the child learns too! (Carla).

[...] I enrolled him in a public school in Santana. My son went there when he was three. He arrived at school, was well received by people! But the pedagogical part has always been impaired. He played with the kids in the park! But the teacher has no training. My son, thank God and this school, in the social part has outdone himself. He came out of his diapers, ate spoon. So, it has evolved, but the pedagogical part to this day is greatly impaired! (Carla).

Inclusion requires a teacher who initially believes that this is necessary and possible and also has technical and pedagogical training to work with children with SEN in the regular classroom. The inclusion policies in Brazil have inserted children in regular schools, but they have not been sufficiently attacked for the training of teachers and adequate conditions for the work of these professionals. According to Mantoan (2003), a teacher training that favors inclusion is one in which they are encouraged to reflect on how inclusion and the best way to occur in different schools, in order to rethink the role of teachers, schools, education and pedagogical practices used so far. Also, according to the author, there are schools that consider themselves unprepared and those that do not believe in the benefits of inclusion, because they consider that students would not be able to follow the others. Thus, the importance arises to propose new pedagogical alternatives that favor everyone, proposing innovation and paradigm breaks for the implementation of inclusive practices that contribute in fact to the integral education of students (CARARA, 2016; CARVALHO, 2012; MENDES; GONÇALVES; VILARONGA; ZERBATO, 2014).

It should be noted that it is foreseen in the Plan of Guidelines and Bases of Basic Education (BRASIL, 2011) that, for the implementation of Inclusive Education, the school needs to provide and provide means for organizing classes so that there are teachers qualified to meet children with Special Educational Needs, as well as propose flexibility and curricular adaptation that consider the needs of these children (KASSAR, 2002). For some theorists, the
difficulties for the implementation of an inclusive educational system in Brazil are of the most varied orders, related either to the organization of society, its hegemonic values, or to the means concretely made available for its implementation (FERREIRA, 2006; CARVALHO, 2004; MENDES, 2010).

Mothers are informed about the rights of their children regarding the need for pedagogical changes so that they can attend school with real use and point to the appropriate changes in the way of thinking about education, which implies collaboration and participation of all those involved in teaching-learning processes.

[...] So, I think it's nice for the school to consider these different degrees of development, more and more, because today people receive more diagnoses than they received before and it is worth turning this into pedagogical evidence. So, in the classroom, when you're going to do the panel, think of a panel that meets everyone! (Denise).

According to the mothers' perceptions, schools gain from receiving a child with ASD or with any other difference, because they open up to new possibilities of thinking about quality education for all. Faced with the challenge of learning to respect singularities, the entire school community is encouraged to work in cooperation, respecting the differences and suiting them since Early Childhood Education, favoring that, in the future, children may participate in a de facto inclusive society. According to Mendes, Vilaronga and Zerbato (2014, p. 72, our translation), "school inclusion requires changes in pedagogical practices, culture, curriculum, activity planning and various perspectives within the school."

[...] We need to understand that it is the school that learns to learn, because if there is an autistic person who needs to discover the various ways to learn, it becomes a more efficient school. If the school is willing to do so, the autistic is a catalyst for human development, if the teacher educates an autistic, she educates any human being. Now, if she refuses to educate an autistic, I really rethink whether she is able to educate any human being (Dulce).

[...] Actually, it's something that enriches the school. I'm thinking so. I think my son, for school, he's not a burden. I think he's an opportunity for school (Julia).

As Evidenced by Mantoan (2003), the success of learning lies in exploring talents, updating possibilities, developing natural predispositions of each student. To include the student with disabilities is not only to allow, by legal means, his/her stay in the regular school, but to make necessary modifications in schools to motivate him/her to participate in educational projects so that he can develop social and cognitive skills.
[...] He knows he has to go, just as he knows he has to sit at the table to have lunch, he goes and sits. So he's more, he's more independent. I think it's better that way, he feels good. It's a place he's wanted, I think he likes the kids too, his way. But he laughs at them, at times he observes. The teachers are overly affectionate with him and so is he (Julia).

[...] It's natural for people to identify themselves and get close to who they're talking about. What appeal do you have who don't talk? Who's going to play along? I keep thinking, "What attractions can my son have?" In a room with 16 children all super social! There was a day when I went to pick him up [...], a little friend came, kissed him on the cheek, looked at me and said, "Did you know that we play together every day?" Denise.

Despite all the difficulties faced, early childhood education schools are in fact understood by the interviewees as important spaces of socialization and development for their children, from which they have gains when living with teachers and colleagues, to the extent that they are stimulated by those around them.

The future of children with ASD

The question that is imposed on children with ASD concerns the transition from Early Childhood Education to Elementary School, taking into account that the expectations regarding the learning of pedagogical contents become more evident.

[...] I'm very afraid of the transition to the fundamental, actually! Because, I don't know, like, in childish you have something more maternal. You have a better welcome; the schools are smaller. I think he stays, he's more protective, you know? I'm very afraid of this transition to the fundamental (Fabiana).

Some narratives denote parents’ concerns about the real possibilities of the child staying in regular school from elementary school. In this sense, some pedagogical actions seek to meet the new demands presented by both students and their teachers, and, consequently, ensure access, permanence and learning in the school space and time, promoting a truly quality education for all.

Collaborative teaching (CAPELLINI; MENDES, 2007; RABELO; SANTOS, 2011), the Universal Learning Design (ROSE et al., 2005) and Information and Communication Technologies (GIROTO et al., 2012) are resources that could be used in the educational context in order to favor the learning of students in general and, in particular, of students with SEN, including ASD. Unfortunately, despite all the inclusive ideas and proposals for innovative and inclusive pedagogical actions and practices, the reality shows that many autistic students end up encountering insurmountable barriers that can start already in Early Childhood Education.
and that are perpetuated throughout elementary and high school, hindering or often preventing the completion of Basic Education and its continuity to Higher Education.

Data from the 2020 School Census of Basic Education\(^8\), released by the Ministry of Education (MEC), the National Institute of Educational Studies and Research Anísio Teixeira (INEP) and the Directorate of Educational Statistics (DEED) \(^9\) indicate the increase in enrollment of students with disabilities, Global Developmental Disorders or High Skills/Giftedness\(^10\) in exclusive common or special classes, especially in schools in the municipal school system. The number of special education enrollments reached 1.3 million in 2020, an increase of 34.7% compared to 2016. The largest number of them are in elementary school, which concentrates 69.6% of special education enrollments.

However, looking at the data more closely and analyzing the numbers and not the statistics, we observed that this is a small number when compared to the number of students who are not classified in these categories. In 2020, in the Initial Years (1st to 5th years), there were 526,326 students enrolled with disabilities, Global Development disorders or high skills and 385,180 more in the Final Years (6th to 9th years), totaling 911,506 students from the target audience of Special Education in the basic education stage. In 2020, 26.7 million enrollments were registered in Basic Education in Brazil, of which 14,790,415 were registered in the Initial Years and 11,928,415 in the Final Years. This means that there are approximately 3.56% students with disabilities, Global Development disorders or high skills in the Early Years and 3.23% in the Final Years. In relation to high school, in that same year, 7.6 million enrollments were registered, 148,513 of which were students with disabilities, Global Developmental Disorders or high skills, representing 1.95% of the total number of students and a sharp decrease in relation to the percentage of students in this category enrolled in the Final Years of Basic Education. Enrollment of students with disabilities also increased in Early Childhood Education. Looking at the historical grade, the inclusion of these students in regular classes increased from 84.2% in 2016, from a total of 75,059 students to 93%, from a total of 110,738 students in 2020. The document states that the largest increase in the proportion of students

---


\(^10\) The author's note: ICD-10 had several diagnoses within Global Developmental Disorders (DGT), such as: Infantile Autism, Atypical Autism, Childhood Disintegrative Disorder, Hyperkinesia Disorder Associated with Mental Retardation and Stereotyped Movements, Asperger Syndrome, Other DGD and TGD without Other Specification. The new version of the classification, cid11, unites all these diagnoses in autism spectrum disorder.
included, between 2016 and 2020, was observed in Early Childhood Education, with an increase of 8.8%.

The last Census of Higher Education 2019, conducted by the National Institute of Educational Studies and Research Anísio Teixeira (INEP), shows that the number of enrollments of students with Disabilities, Global Developmental Disorders or High Skills/Giftedness increased from 20,530 in 2009 to 48,520 in 2019, corresponding respectively to 0.34% and 0.56% of the percentage in relation to the total number of undergraduate enrollments. Considering THED as described in DSM V and ICD 11, covering the previous classifications of Childhood Autism, Childhood Disintegrative Disorder and Asperger's Syndrome that the census still names and presents in the document, there are about 1,800 students enrolled in undergraduate courses throughout the country. Considering the overall total of 3,625,915 undergraduate students throughout the country, between face-to-face modalities (2,034,126) and EAD (1,591,789), in the sphere of federal, state, municipal and private institutions, the number of autistic students entering is quite small, corresponding to 0.049% of the total. In addition to this worrying scenario, there is no data on how many students with ASD actually complete this stage and are effectively admitted to the labor market.

Another important fact is that most students with disabilities, however, do not have access to specialized educational care (ESA), and only 37.5% use the service, 55.8% are included in a common class without ESA and 6.7% are in a special class. Therefore, the increasing number of enrollments in both the initial and final series does not necessarily represent the permanence and completion of studies by this population. Thus, the special school presents itself to some families as a possibility, but loaded with meanings that deviate from the inclusive proposal.

[…]. Oh, it's very difficult, because when you walk into a special school and see the big kids, you project your child and then you see a reality that's not what you wanted, right? (Dulce).

[…]. It's hard. But my husband gets kind of like that, putting it in special school, because they say it's like this: when you put it in a special school it's over! Then he's going to be there for the rest of his life (Carla).

According to Mendes (2019), in general, there has been little controversy when talking about school inclusion in the case of students with mild difficulties, who make up approximately 80% of the students of the Special Education Target Audience (PAEE) and require only a supported schooling and a good quality school. However, consensus decreases when it comes to about 20% to 25% of students who require teaching specificities that are not
necessarily compatible with common-class schooling, such as moderate-level sensory and intellectual disabilities, as well as marked and complex language disorders.

And besides elementary school, what's going to happen? The mothers' narratives denote that it is not possible to think about the beginning of schooling without considering its completion and, even more, without reflecting on the difficulty of conceiving a life project for a child with ASD beyond the school stage. According to Schmidt and Bosa (2003), several studies reveal that families of autistic children live in situations of continuous stress, presenting much higher standards than those of the other. This stress is related to the specific characteristics of the disorder that require a lot from family members, the developmental delay and expectations of the future for a person with ASD in the face of the obstacles to be faced.

[...] When we think about schooling is the first day of the child in school that you design until the last and in the case of an autistic child has no project. There is no project, no one knows, no one guarantees and has no public policy to assist families who have people with disabilities! (Dulce).

[...] You know, if God gave us to create, we want them to mature. You want them to work. You want them to have a normal life, but then we're fighting for it! We don't know if they're going to have it or not. So our concern is that we are not eternal! So if one day we go from here, who's going to take care of them? We need to do our utmost to make them dependent on themselves so we can be calm! (Carla).

[...] I don't refuse to take care of my son, but I just wanted to know what's going to happen to him when I die. That's it, that's it! Because right now I'm not going to refuse to take care of my son, but when I die, I don't think I'm going to be able to take care of him. And then no one has that answer (Dulce).

[...] Where he's going to get to I don't know, but he's going to get somewhere! And all that he has at school today, it's going to be important for him to get there. I want him to learn and, regardless of the difficulties he has, I intend to find ways to get him there! (Denise).

Final considerations

The path taken by the investigation led to important push-ups about the relationship between school and family with regard to the education of children with some disability or difference, specifically in this study, students diagnosed with ASD. The mothers' narratives reveal that the entry of these children into school, in addition to triggering a family movement in order to understand the experience of human existence considered as different, provokes an intense search for school and social inclusion that are rightful to them. However, the narratives brought to light the perceptions of these women about the difficulties faced by them daily
regarding the inclusion of a child with ASD in regular schools, which, in general, are still unprepared.

Faced with a demand by the school, families are impelled to the task of adapting their children to a pedagogical context based on principles that gave support to modernity and that are shown to be outdated, even if they are neurotypical children: a content school model and focused, in most cases, the preparation of typical people for admission to higher education and, later, in the labor market. Significant changes are urgent in the stereotyped and prejudiced paradigm based on a Medical Model that we have historically inherited and which is still present in postmodern society in relation to disabilities. The Medical Model that recognizes in injury, disease or physical limitation the first cause of social inequality and disadvantages experienced by disabled people still prevails in the manifestations of previous paradigms, such as exclusion and social segregation. But today we know the role of social structures for the oppression and marginalization of the disabled person. According to Social Model, we understand that disability is not an individual problem, but a collective issue. This new understanding transfers responsibility for the disadvantages of the individual's limitations to society's inability to predict and adjust to diversity. Being, therefore, understood as having a structural cause, what measures can be taken to build a society based on the Paradigm of Inclusion? We must review what the role of the school is, after all, in this process.

Despite the difficulties faced daily, the research participants confirmed that the school, although needed and reformulations, is perceived by them as an important space for socialization and the construction of bonds, learning and construction and skills development. But at the end of this academic trajectory, either because it has actually been fulfilled or simply abandoned in the face of so many accessibility barriers imposed, the uncomfortable question arises: how will the future of a young ASD in Brazilian society today be? It was evident that families feel unwatched by the lack of public policies focused on this issue and by the State, due to their inoperability and that, poorly or well-prepared, the school represents the only possible way of social inclusion for many families.

Inclusive Education is an integral and fundamental part of Social Inclusion. Both are moving processes that are still surrounded by uncertainties and doubts about how to affect them. However, a sense of humanity and guarantee of civil rights, so necessary to accept and live with what is different, is established in contemporary societies, despite their advances and setbacks. We must be vigilant in order to contribute to the fight against discrimination and prejudice against diversity. Even though they don't know about the future, atypical mothers hope to walk with their children on a built-by-step path. However, for this to be possible, these women need
to have a system of care and care composed of a set of effective public policies and social support networks that provide adequate conditions of care for both the autistic person and themselves, their main caregivers. And the school plays a key role in this system.

ACKNOWLEDGMENTS: The research was supported by CAPES in the form of a master's scholarship.

REFERENCES


CARVALHO, R. E. **Com os pingos nos “is”**. Porto Alegre: Mediação, 2004.


Como referenciar este artigo

TAMBARA, M. P.; FURLANETTO, E. C. Autistic children mothers' narratives about the first school experiences in early childhood education. Revista @mbienteeducação, São Paulo, v. 15, n. 00, e022024, 2021. e-ISSN: 1982-8632. DOI: https://doi.org/10.26843/ae.v15i00.1167

Submitted: 19/02/2022
Revisions required: 03/04/2022
Approved: 20/08/2022
Published: 29/12/2022