

Original Article

# Experience of family members of children with disabilities in the process of school inclusion in the regular public education system: a case study

*Experiências de familiares de crianças com deficiência no processo de inclusão escolar na rede pública regular de ensino: um estudo de caso*

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## Abstract

**Introduction:** To respect human diversity and meet different educational needs, the schooling process requires dialogue and shared efforts between educators, families, and students. **Objective:** This study aims to analyze how family members of children with disabilities enrolled in the regular public education system of the municipality of São Paulo understand the impact of schooling on their everyday lives. **Method:** A descriptive case study was conducted. Four mothers of children with disabilities enrolled in the 1st cycle of elementary school were interviewed. After the intentional selection of the first participant, the others were identified using the Snowball Sampling method. Data were collected through semi-structured interviews and analyzed using thematic content analysis. **Results:** Four thematic cores were identified: 1) the relationship between family and school; 2) the school and the process of school inclusion for students with disabilities; 3) the impact of schooling on the everyday lives of students with disabilities and their families; 4) the role of the mother and support networks in the schooling of children with disabilities. The mothers reported difficulties in their relationship with the schools. They noticed that the schools implemented actions that hindered the participation of students with disabilities. They relied on the support of other mothers of children with disabilities to ensure their children's right to education. Aside from improvements in socialization, no significant impacts of schooling on family life were observed. **Conclusion:** It is necessary to rethink the role of schools in the construction of a transformative education for all. The occupational therapist can act as a facilitator in this process.

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**Keywords:** Family, Mainstreaming, Education, Education, Occupational Therapy, Disabled Children.

### **Resumo**

**Introdução:** Para respeitar a diversidade humana e atender às diferentes necessidades educacionais, o processo de escolarização requer diálogos e construções compartilhadas entre educadores, famílias e estudantes. **Objetivo:** Este estudo visa analisar como familiares de crianças com deficiência matriculadas na rede pública regular de ensino do município de São Paulo compreendem o impacto da escolarização dessas crianças em seus cotidianos. **Método:** Realizou-se um estudo de caso descritivo. Foram entrevistadas quatro mães de crianças com deficiência estudantes matriculadas no 1º ciclo do ensino fundamental. Após a seleção intencional do primeiro participante, os demais foram identificados via método Bola de Neve. Os dados foram coletados por meio de entrevistas semiestruturadas e analisados segundo a análise de conteúdo temática. **Resultados:** Quatro núcleos temáticos foram identificados: 1) a relação entre família e escola; 2) a escola e o processo de inclusão escolar de estudantes com deficiência; 3) os impactos da escolarização no cotidiano de estudantes com deficiência e seus familiares; 4) o papel da mãe e das redes de apoio na escolarização dos filhos com deficiência. As mães relataram dificuldades na relação com as escolas. Perceberam que as escolas implementaram ações que dificultaram a participação de estudantes com deficiência. Contaram com o apoio de outras mães de crianças com deficiência para assegurar o direito à educação de seus filhos. Além da melhoria na socialização, não foram observados impactos significativos da escolarização no cotidiano familiar. **Conclusão:** É necessário repensar o papel das escolas na construção de uma educação transformadora para todos. O terapeuta ocupacional pode atuar como facilitador desse processo.

**Palavras-chave:** Família, Inclusão Escolar, Educação, Terapia Ocupacional, Crianças com Deficiência.

## **Introduction**

### **Disability, school inclusion, and everyday life**

According to the Convention on the Rights of Persons with Disabilities, ratified in Brazil by Legislative Decree No. 186 of 2008:

Persons with disabilities are those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (Brasil, 2008a).

The convention aligns with the debates of the Social Model of Disability, emphasizing the need for a complex understanding of the concept of disability. It recognizes the body beyond injury and incapacity, considering collective and social

aspects, and denounces the social structures that oppress people with disabilities (Diniz, 2007). The importance of the interaction between the individual and the environment, as well as barriers, whether physical or attitudinal, is also highlighted.

This model, which began to take shape in the 1970s, proposes a perception that challenges the biomedical model, which views disability as injury and limitations, targeting the disabled body for interventions. For the first generation of theorists of the Social Model of Disability, independence is understood as an ethical value for human life. According to this model, disadvantages stem more directly from barriers than from injuries; therefore, by removing barriers, people with disabilities would demonstrate their productive capacity and be independent (Diniz, 2007).

As of the 1990s, criticism has emerged regarding the emphasis on independence, with the introduction of postmodern approaches and feminist critiques, defining a second generation of the Social Model of Disability. This second version argues that the overemphasis on independence overlooks the diversity of disability experiences, as not everyone can live in full independence on an individual level (Diniz, 2007).

In contrast to the ideal of independence, this new generation of the model introduces the concept of interdependence more broadly, not limited to the debate on people with disabilities. The Social Model of Disability, from the perspective of Feminist Disability Studies, considers factors of intersectionality with social markers such as age, gender, ethnicity, and social class (Gomes & Lopes, 2017), and places interdependence as a central theme in the lives of individuals, also discussing what it means to live in a disabled body (Diniz, 2007).

Based on this concept, it is possible to discuss social barriers without excluding bodily aspects and the fact that dependencies can exist without preventing the social participation of people with disabilities (Diniz, 2007). This study is grounded in this perspective on disability.

Thus, a parallel can be drawn between school, family, and the individual, as these three elements are closely linked and need to function interdependently to ensure participation, especially when considering Inclusive Education (Rocha et al., 2022). The interaction between school, family, and student creates a reciprocal relationship, impacting and being impacted by the lives and daily routines of students and their families (Rocha et al., 2022).

Given this, actions aimed at constructing an inclusive school should not use the independence of students with disabilities as a criterion for their participation in activities and the school environment. On the contrary, inclusive actions should foresee and facilitate interdependence, enabling the participation of all, while considering and respecting human diversity.

The family establishes and organizes the child's first relationships, their initial contacts outside the home, ideally providing an environment for growth and development (Rocha et al., 2022). Therefore, the family strongly influences the child's actions and personality formation. In the relationship between school and family, it should not be expected that family members have specific training in the fields of pedagogy or disabilities, but rather value the fact that the family lives with the student and provides the foundation for their personal development and the resources to strengthen them socially and emotionally to face challenges (Rech & Freitas, 2021).

According to Dessen & Polonia (2007), the family and the school emerge as fundamental institutions in triggering the developmental processes of individuals, acting as catalysts or inhibitors of their physical, intellectual, emotional, and social growth.

Reali & Tancredi (2005) state that if the school and family establish a common language and collaboratively defined strategies regarding certain aspects of student development and education, a more meaningful academic path can be created. Thus, good interaction between family and school leads to a more comprehensive understanding of students' interests, abilities, needs, and potentialities.

It is important to emphasize that school inclusion is based on heterogeneity, not homogeneity, in favor of issues such as socialization and learning, as well as coexistence with differences. In this regard, the family can also be invoked, as:

The relationship between school and families, given its complexity, should be addressed within the scope of each specific reality. Schools are not all the same—although governed by the same legislation and pursuing corresponding goals—and family environments are unique, although they share similarities (Reali & Tancredi, 2005, p. 241).

When considering the school as a space of learning and socialization, it is important to note the significant difference between regular and special schools, given the foundations upon which work is developed in these institutions. Special schools are based on a segregationist model, dividing students by pathology from a biomedical logic. Inclusive regular schools, on the other hand, provide the experience of coexistence with differences, aiming for a more democratic education for all. In general, the concept of inclusive education arises from issues raised by disability but is not limited to them, as the school itself must be rethought as a school for all (Nunes et al., 2015).

The interaction with other children, with other differences, the possibility of academic progression, and broader social relations have brought many challenges, as social participation is also difficult, but have expanded horizons and new life projects for people with disabilities and their families, as well as for the groups with whom they have come to interact (Rocha & Souza, 2018, p. 31).

In addition to the benefits of learning and socialization, enrolling children with disabilities in schools, fulfilling mandatory education requirements, contributes to increasing the country's school enrollment rate (Kassar, 2016).

Thus, regular schools cannot neglect the specific educational needs of students with disabilities, nor should they focus solely on aspects related to their socialization, as they are not specialized institutions for the education of these students (Brasil, 2008b).

The National Policy on Special Education from the Perspective of Inclusive Education (Brasil, 2008b) affirms the need to meet the special educational needs of students with disabilities, global developmental disorders, and high abilities/giftedness in regular schools, without creating special educational environments within the schools or specialized institutions to replace regular schools. Therefore, it is in regular schools where the most diverse content is taught and learned, where socialization, social participation, and citizenship of all students are promoted.

It is important to consider the particularities of students with disabilities, constantly linked to the education of students without disabilities, as an integrated whole (Nunes et al., 2015), since isolated actions aimed at only one student are not very effective in the school environment.

The Brazilian Inclusion Law (LBI) reiterates the right of people with disabilities to access all educational levels throughout life, as well as their right to achieve “[...] the maximum possible development of their talents and physical, sensory, intellectual, and social abilities, according to their characteristics, interests, and learning needs” (Brasil, 2015).

On the other hand, contemporary family and school environments are spaces where children often spend a significant amount of their time, profoundly impacting the construction and organization of their everyday lives. As Galheigo (2003) points out, the State, institutions, and corporations are tenacious producers and controllers of everyday life.

For Heller (1985, p. 17), “[...] everyday life is the life of the entire human being; that is, man participates in everyday life with all aspects of their individuality and personality”, making it an inescapable human experience that crosses the very condition of being human and reveals itself as a historical narrative situated in time and space. This author, by defending that everyday life is human life, affirms that the individual is always simultaneously a particular being and a generic being. This means that the individual transforms into the collective subject, whether through artistic, labor, or scientific activity, through caring for others (children, sick and needy persons), or through activities related to social, political, and solidarity participation (Galheigo, 2003).

### **Considerations on occupational therapy and school inclusion**

According to Resolution No. 500 of the Federal Council of Physical Therapy and Occupational Therapy (COFFITO), dated 26 December 2018, “[...] the role of the Occupational Therapist in the School Context aims at the student’s occupational performance in various learning spaces by developing actions that promote this objective” (Brasil, 2018).

The occupational therapist, in turn, can act as a facilitator in the educational process, which, as Jurdi et al. (2004, p. 27) state, “[...] occurs through encounters that provide access to knowledge that enables the individual to appropriate the human world”.

According to Pereira et al. (2021), it is important for occupational therapy to reflect on its participation in the school context, considering the access, permanence, and quality of learning for children, adolescents, and young people in school education as a human and social right. When a practice is built based on the perspective of education as a right and the need for regular schooling for all, one that considers individual needs and seeks to humanize those involved, it actively contributes to the inclusion of marginalized groups. This study specifically focuses on students with disabilities, among many other groups that should not be rendered invisible in the educational process.

When specifically considering students with disabilities and the practice of occupational therapy in the school context, various potential interventions can be envisioned, from adaptations of educational materials and curricula to the use of assistive

technologies, playful activities, environmental comfort seeking to eliminate architectural barriers, and even socialization efforts (Rocha, 2007). These interventions can be directed not only at the students but also at the school's administration, coordination, and other educators (Rocha, 2007).

Thinking about interventions that consider the student with disabilities, educators, physical space, and family comes from premises that focus on the broader school context and collectives (Rocha, 2018). This means that such interventions stem from an approach that views the educational environment as composed of different groups that interact and influence each other daily, capable of bringing about transformations in the everyday life of all involved.

Considering all these factors, it is necessary to emphasize that the school is a space for learning, socialization, coexistence, social participation, and citizenship, not a clinical space. The special needs of students with disabilities must be considered by occupational therapists outside of a corrective or interventional logic, as often occurs in a clinical health setting (Rocha, 2007; 2018). Therefore, an occupational-therapeutic approach specific to the school and educational field must be developed.

This study aims to analyze how families of children with disabilities enrolled in regular elementary education in the public school system of the municipality of São Paulo understand the impact of their children's schooling on their everyday lives.

## **Method**

This qualitative research employed the descriptive case study method with four families of children with disabilities. Yin (2001) states that case study is a research strategy that seeks to examine a contemporary phenomenon within its context. Andrade et al. (2017) emphasize that case study is an appropriate methodology when seeking to answer questions that explain the current circumstances of a social phenomenon, formulating how a particular social phenomenon functions. This method allows for capturing various dimensions of a specific issue. In this study, the case being examined is the school inclusion of children with disabilities in the regular school system of the state of São Paulo's capital.

Here, more than one family was interviewed, not with the intention of statistical representation, but to collect data that allow for comparisons between "[...] different complexities surrounding a common problem" (Almeida, 2016, p. 65).

Data were collected through semi-structured interviews with family members of children with disabilities enrolled in public schools in the city of São Paulo, from the 1st to the 5th grade of elementary school.

The semi-structured interview was chosen to collect the data because it allows participants to refer to important aspects of their life experiences while enabling the researcher to be guided by a script, ensuring that the necessary points are addressed (Minayo, 2014).

The interview guide included guiding questions aimed at understanding the journey of students with disabilities and their caregivers up to the children's enrollment in school; after enrollment, how caregivers evaluated the relationship with the school and the relationship of the child with disabilities with other children at the school; the main benefits identified by caregivers regarding the enrollment of children with disabilities in schools and the impact of this enrollment on the families' everyday lives; as well as identifying whether caregivers of

children with disabilities had contact or support from social movements, organizations, and collectives to secure their children's right to education.

The inclusion criteria for participation considered any person with a family connection to the child with disability, who was a student in the regular public school system and acted as a caregiver; family members of any age, social class, or educational background; family members of children with any type of disability (physical, intellectual, sensory, multiple); family members of children who had studied exclusively in public institutions and were enrolled between the 1st and 5th grades of Elementary School (*Ensino Fundamental I*) in the city of São Paulo.

Exclusion criteria for participation in the study included family members of children who were out of school or outside of Elementary School; caregivers who were not family members and/or were professional caregivers; people who did not live in the city of São Paulo; children enrolled in private and/or special schools.

The first family member interviewed was selected intentionally. The snowball method was used to choose the other participants, meaning that after contact with an initial participant, they referred a second participant, who, after the interview, referred a third, and so on (Atkinson & Flint, 2001). This sampling method, which relies on referral networks, is useful for studying sensitive issues that require the knowledge of people within a particular group (Vinuto, 2014).

The researcher contacted these individuals to verify if they met the inclusion criteria. If so, the best day and time for the interview were scheduled. The interviews were conducted online to facilitate participation in a city like São Paulo, which faces many accessibility issues. Before the interview, an Informed Consent Form (ICF) was presented and discussed with participants, who could review the document alone or with a person they trusted. If they agreed, they signed it, and only then were the interviews conducted.

A total of 11 family members were contacted: four did not respond and two did not meet the inclusion criteria, resulting in five completed interviews. However, one of the interviews had to be excluded because the participants did not meet the inclusion criteria of studying in the city of São Paulo, which was only discovered during the interview.

The first interviewee, who initiated the snowball referral process, was chosen because they were a family member of a student with disabilities attending a municipal school in São Paulo where one of the researchers was conducting curricular internship activities.

After the data collection phase, the obtained data underwent thematic content analysis, identifying key themes that composed a communication, the presence or frequency of which had significance for the intended analytical object (Minayo, 2014). This data analysis methodology involves the following steps: pre-analysis, a review of specific literature, and the analysis of the main ideas and meanings obtained. Subsequently, the material was explored to classify, analyze, and decode words, expressions, excerpts, and records, both explicit and implicit, to categorize the obtained content. Finally, the results were processed and interpreted, proposing inferences and making interpretations by linking the theoretical framework with the obtained results (Minayo, 2014).

As a result, four main themes were identified, as presented in Table 1: (1) the relationship between family and school; (2) the school and the process of school inclusion of students with disabilities; (3) the impacts of schooling on the everyday life of students with disabilities and their families; (4) the role of the mother and support networks in the schooling of children with disabilities.

**Table 1.** Themes initially identified during the reading of the interviews and the main sense-making cores identified during data analysis.

<b>Identified themes</b>	<b>Main sense-making cores</b>
Conflicting relationship between school and family	Relationship between family and school
Positive relationship between school and family	
Contact with educators	
Possibilities for communication with the school	
Communication mediated by the right to education, public policies, and legal actions	The school and the process of inclusion of students with disabilities
Knowledge about the right to education	
Exclusionary stances adopted by the school	
Inclusive stances adopted by the school	
Changes in the everyday lives of families after the enrollment of children with disabilities in school	Impacts of schooling on the everyday lives of students with disabilities and their families
Impacts on child development observed after children with disabilities enter school	
Impacts on social participation observed after children with disabilities enter school	
Correlation between attending therapy/rehabilitation and attending school	The role of mothers and support networks in the schooling of children with disabilities
Mothers as managers of the everyday lives of children with disabilities	
Changes in the lives of mothers after the birth of children with disabilities	
Impact school attendance on the everyday lives of mothers	

**Source:** Prepared by the authors, 2024.

Since this study involves human subjects, in accordance with Resolution No. 510, dated 7 April 2016 (Brasil, 2016), it was submitted to the Research Ethics Committee and was approved under protocol CAEE 71630123.6.0000.0068. The study only began after obtaining this approval.

## Results

### Characterization of the participants

Regarding the interviewees, all four were female, married, and mothers of children with disabilities. They reside in different regions of the municipality of São Paulo (Center, West, East, and South). Their ages ranged from 30 to 44 years and their educational level varied from incomplete elementary education to completed higher education degree. All reported not working outside the home, dedicating themselves exclusively to household chores and caring for their children. To preserve their identities, the participants will be referred to as M1, M2, M3, and M4. One of the mothers has twins, both with disabilities, so although there are four mothers, this study refers to five children. The characterization of the participants is presented in Table 2.



The ages of the children with disabilities ranged from 6 to 10 years. Four are male and one is female. Four study at Municipal Elementary Schools (EMEF) that are part of Unified Educational Centers (CEU)<sup>1</sup>, while one attends a traditional EMEF, outside the CEU structure. Regarding the disabilities, three children are diagnosed with Autism Spectrum Disorder (ASD), with two of them having additional associated disabilities. Three children have cerebral palsy (CP): one of them with low vision and associated ASD and another with associated intellectual disability. One of the children has spina bifida, ASD, and associated low vision. The distribution of clinical conditions is detailed in Table 2. Of the five children, two attend school every day for the entire school period, and three attend school at specific times and days previously agreed upon between the families and the schools.

**Table 2.** Caracterização dos participantes do estudo.

Participant	Age (years)	Education / Occupation	Parental relationship	Total number of children	Child(ren) with disability	Grade in Elementary School	Region of residence	School region	School (EMEF)
M1	37	Incomplete elementary education / homemaker	Mother	2	1 boy and 1 girl (6-year-old twins). Both have cerebral palsy. The boy has associated intellectual disability that is more severe than that of the girl in motor terms.	1st year	West	West	EMEF in a CEU
M2	44	Complete high school / homemaker	Mother	1	1 boy (10 years old) with Autism Spectrum Disorder, cerebral palsy, and low vision	5th year	East	East	EMEF in a CEU
M3	30	Bachelor's degree in law / homemaker	Mother	1	1 boy (8 years old) with Autism Spectrum Disorder	2nd year	South	South	EMEF in a CEU
M4	33	Complete high school / homemaker	Mother	1	1 boy (8 years old) with Autism Spectrum Disorder, Fragile X Syndrome, and spina bifida	2nd year	Center	Center	Traditional EMEF

**Source:** Prepared by the authors, 2024.

## Relationship between family and school

In this category, an attempt was made to understand how the relationship between the family and the school occurs, identifying facilitators or barriers in this relationship.

<sup>1</sup> According to the São Paulo City Hall, the mission of the CEUs is to promote education for the entire population in a complete, democratic, emancipatory, and humanized manner, integrating education, art, culture, leisure, sports, and recreation (São Paulo, 2024).

The interviewees describe a varied relationship between the school and the family, which depends on both the parents' and the school's openness to dialogue. While some mothers report maintaining direct contact with the school, others describe having more challenging communication, which needs to be mediated by other entities, including filing complaints against the schools. All interviewees mentioned that the mothers take a leading role in the dialogue with the schools.

*He [son] keeps complaining that he doesn't want to go to school, and I was uncertain because he used to cry so much saying he wanted to go to school, but now he doesn't want to go anymore. So I went there [to the school] and cleared up my doubts about what was going on (M1).*

*After I filed the complaint with the Regional Directorate of Education, at CEFAP<sup>2</sup>, I almost reached the last legal instance, and it improved because then my contact was directly with the teacher and principal, not with the inspectors [...]. Then it got better (M2).*

*[...] I now have closer contact with the school staff as a whole, so things have become easier. [...] For instance, there was a time when he didn't want to go into the school, so I scheduled a meeting with the school to talk and try to adjust, and it worked. So, they help whenever possible (M3).*

*I completed the enrollment and then went and talked to her [the teacher]. Because he [son] had a therapeutic companion who was from the clinic where he undergoes therapy. I needed to know if they [the school] would allow her to come in, stay with him and such [during school hours]. They allowed it. That part was very smooth. And then I kept talking to see what his day-to-day would be like (M4).*

These results align with the discussions by Almohalha et al. (2021) and Rocha et al. (2022), who assert that the schooling experiences of students with disabilities, as reported by parents, are heterogeneous and depend on the relationships built between the families and the school in which the child is enrolled. According to Rabelo & Magalhães (2021) and Silva (2022), a good relationship between the school and the family contributes to the inclusion of the child with disabilities in the school.

The interviewees acknowledge that knowing their children's rights was necessary for negotiating with the school regarding enrollment, inclusion, and participation of the children.

*It was quite complicated [to enroll him], because when I explained his case, they didn't really want to accept him [at the school], there was always some difficulty. I even had to keep following up and calling the school for them to accept him, but it worked out! (M1).*

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<sup>2</sup> Center for Training and Support for Inclusion of the São Paulo Municipal Department of Education. An institution that provides support to schools and students with disabilities in the São Paulo municipal public education network.

*In the first grade, I went to talk to the principal, actually the pedagogical coordinator. I explained his condition and how he would be attended to in the classroom. To understand and do the best for him, because he has rights (M4).*

In addition to recognizing the right to access education, the interviewees mentioned the need to understand the right to access transportation, as well as the right to access other sectors and the city. This demonstrates that the realization of the right to education is closely linked to other struggles for access rights for people with disabilities within the city.

*What made things easier was the preferential spot that I didn't know existed [in transportation]. He would only be able to attend school if he had school transportation, because since he is a wheelchair user, he wouldn't be able to go to school without transportation<sup>3</sup>, so I went on with that information. [...] his place [at the school] is already guaranteed, without transportation. As soon as the place is assigned to him, his transportation must also be guaranteed (M2).*

These data reinforce the findings of Ignácio & Uhmman (2021), who report that some families are constantly fighting for the right to education, often making it necessary to resort to legal action to ensure these rights are fulfilled. Rabelo & Magalhães (2021) emphasize that a portion of families of people with disabilities view the policies positively, which contributes to the guarantee of rights.

### **The school and the process of inclusion of students with disabilities**

Here, the aim was to understand how the families of students with disabilities evaluate the actions taken by schools in the process of school inclusion.

The interviewees identified an exclusionary stance on the part of the schools. Even the mothers who stated that their children are included in the school mentioned difficulties in this process at some point.

*[...] when I explained his case [the child with a disability], they kept saying there were no places available (M1).*

*He was excluded from a field trip, no one informed me, no one told me about the trip, and he was excluded. In my mind, it was to avoid the trouble of caring for him there. He and another child with Down syndrome were both excluded. So, he came back home, but that day I didn't know, they just told me that there were no classes for his class (M2).*

*There are issues that are really difficult... they don't understand what autism is. The school itself doesn't understand what it is. So, you have to explain what it is,*

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<sup>3</sup>The São Paulo Municipal Government guarantees free school transportation for all students with disabilities, global developmental disorders, and high abilities/giftedness enrolled in municipal schools, as well as for their siblings up to 11 years old who attend school during the same period as the students with disabilities. It is not necessary to request transportation, as students eligible for the service are automatically identified by the system through their registration data at the time of enrollment or re-enrollment. In general, families are also informed about the right to transportation during the enrollment and re-enrollment process (São Paulo, 2023).

*how it works, how your child is. I think it's also a lack of interest from part of the school staff and from the school as a whole (M3).*

*So I found the teacher a bit... she wouldn't come and ask me "Oh, M4, how should I do this?" She wouldn't accept input. I think she, in that regard, didn't really want much contact... but later she started to open up (M4).*

The interviewees' narratives align with the discussions by Rabelo & Magalhães (2021) regarding attitudinal barriers in schools, including stereotypes and prejudices against children with disabilities, particularly those with intellectual disabilities, as one of the main factors leading to the exclusion of these children from regular schools.

Rocha et al. (2022) report that schools often adopt an approach towards students with disabilities as if they were incapable of fully participating in school activities, even though these students have shown abilities to do so. This highlights the central role of attitudinal barriers in the schooling process of students with disabilities.

As facilitators of the inclusion process, the interviewees mentioned the adaptations made by schools to meet the needs of students with disabilities in terms of content learning. These adaptations are recognized by them as positive and necessary measures in their children's educational process.

*I even told [the school] that I. [son] was different from the other children, and the way to handle him was different. Then they asked me to bring a medical report so they could do activities with him, to stimulate him. I thought that was nice because I didn't know. If I had known, I would have taken the report earlier (M1).*

*[...] there is a person from the municipality who assists him [son]. But the issue is whether he wants to do the activities sometimes. However, they [the school] guide him to do them, they help, they provide more adapted materials. So he is able to do some things, but not others, often because of his lack of interest. But they always encourage him to participate, even on field trips, he's always included (M3).*

*I think they [the school] try to include him. Because his materials, the teacher made a booklet with activities for him. Drawing, painting, gluing, those kinds of things. And she [the teacher] sits with him and does them, either her or the intern (M4).*

Despite the interviewees valuing the adaptations made by schools, some, like M2, perceive that certain adaptations are designed to distract or quiet students with disabilities:

*So, he comes with a little rattle that they [the teachers] make to distract him, they make something for him to hold and play with, but as for worksheets, writing, or any kind of paper activity... no. That doesn't happen. She [the teacher] always says she's looking for the best way, figuring things out (M2).*

Silva (2022) and Almohalha et al. (2021) highlight the need for specific and differentiated teaching intervention strategies aimed at equalizing, interacting, and socializing students with disabilities so that everyone learns together. Meanwhile, Rocha et al. (2022) and Rabelo & Magalhães (2021) discuss the importance of considering the educational needs of students in the construction of adaptations.

The interviewees mention the challenges faced by students with disabilities who encounter barriers that go beyond the pedagogical aspects, also relating to physical spaces and accessibility, both at school and during the journey from home to school, which again reveals the existence of numerous exclusionary barriers beyond the field of education:

*They [school transportation] still pick him up down the street, and sometimes it's not great. Because they [school transportation] should be coming up here [to the house of the student with a disability]<sup>4</sup>. And sometimes it's difficult, on rainy days it's hard for us to go down. Besides, C. [daughter with a disability] doesn't stay in the chair<sup>5</sup> and there's a risk she could get hurt, like when she fell once. But we keep going with what we can. [...] And now, it's even worse because I. [son with a disability] is heavier, and the descent is hard for us, because sometimes... the chair goes down too quickly, and you have to be very careful (M1).*

*I had a lot of problems with the elevator being broken or with the person at the gate [of the school] receiving him in bad faith, because before he even entered, they would tell the van driver that the elevator was broken and that he should take him back home. And then I found out that the elevator wasn't broken; they simply wouldn't let him into the school (M2).*

*At the school, there are stairs. I think they could also change that, you know? Make a little ramp. There are two flights of stairs [...] And he doesn't know how to go up, he throws himself. There's a handrail, but he's afraid (M4).*

Specific literature highlights the importance of accessibility in ensuring access, mobility, and participation of students with disabilities in school (Rabelo & Magalhães, 2021; Rocha et al., 2022; Silva, 2022). Rabelo & Magalhães (2021) also identify that some students with disabilities face difficulties with the accessibility of school transportation, corroborating the findings of this study.

### **Impacts of schooling on the everyday lives of students with disabilities and their families**

In this category, the aim was to understand the impacts observed by the family in everyday life after the enrollment of children with disabilities in school. The interviewees

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<sup>4</sup>The interviewee complains about the fact that the school transportation does not reach her residence, which is located in a highly inaccessible area. There is a possibility for the school transportation to pick up her two children with disabilities at her doorstep, but this would require the driver to perform a maneuver on a very steep street, which does not happen. As a result, M1 has to take her children to a wider and flatter street, about a block away from her home, for them to board the vehicle.

<sup>5</sup> M1's two children have cerebral palsy but with distinct limitations. I. requires a wheelchair as he is unable to walk, while C. does not need one, as she can walk, though she has equinus foot deformity, which makes walking difficult, especially on rainy days, because of the uneven terrain of the neighborhood.

reported noticing benefits of schooling in the everyday lives of families, the main one being an improvement in socialization:

*I think the influence of the school on socialization just added to the other things he had been gaining. Because before he started school, he was already undergoing therapy and follow-ups (M2).*

*At school, he has more contact with other children, playing together, during recess, in the classroom, and during mealtime. So, it really helped with that integration, which wasn't happening before. He didn't want to participate much (M3).*

*And the school helps me a lot. Since he is not undergoing therapy and is attending school, I thought he would become more anxious, but no, he's been fine. It helped me a lot. At school, they have the AEE<sup>6</sup>. They [students with disabilities] have a room adapted for them. So, every week, once a week, he goes there [to the AEE], and there's a teacher who stays with him (M4).*

Several authors highlight the importance of the socialization promoted by the school, enabling an increase in relationships with other children, exposure to different situations and realities, and the expansion of participation opportunities and support networks (Almohalha et al., 2021; Rabelo & Magalhães, 2021; Rocha et al., 2022).

Some mothers are surprised by how much their children enjoy and want to go to school, even when they face situations of prejudice. The fact that their children like school also motivates the mothers to keep them attending it regularly:

*I tell you from the bottom of my heart, my son is still in school only because he likes it. Not because of the law, or because I have to put him in... no, I don't have to do anything. I am his mother, and I'm the one who feels the exclusion and prejudice he faces, because he still doesn't understand what he's going through. But the person pushing his wheelchair understands very well (M2).*

*I see him more active, more relaxed. And that was something I was a bit unsure about. I used to think, "Wow, he's going to start school, and he won't even want to go in." But no, I think it's going well (M4).*

Another interviewee identified her child's difficulty in adapting to the transition into elementary school after leaving early childhood education, where other resources, such as playful activities, were used:

*Since he left EMEF<sup>7</sup>, I've noticed a change in him [son]. He's starting to complain, and I think it's because he changed schools... at the other one, he mostly played, and now at this one, he keeps crying, saying he doesn't want to go (M1).*

Despite the changes they notice in their children after starting school, some interviewees have difficulty identifying daily changes resulting from the participation of

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<sup>6</sup>Specialized Educational Assistance.

<sup>7</sup>Municipal School of Early Childhood Education.

children with disabilities in school, even when they report alterations in the family routine:

*I tell you that it doesn't affect anything [going to school]. [...] What changes in the routine is waking up earlier, because he normally wakes up early, but he stays at home, in the home environment. When he goes to school, he gets more tired. [...] That's the difference (M2).*

*At home, I can't say that it has any influence, because the activities he does are only at school. They don't send home activities or homework anymore (M3).*

Ignácio & Uhmman (2021) and Rabelo & Magalhães (2021) state that the inclusion of children with disabilities in school alters family dynamics, which undergoes changes in routine but also involves the construction of new perspectives and expectations regarding the child's development. The change in routine is identified by the interviewees, but there is little discussion about the shift in perspectives and expectations for the children's future.

### **The role of the mother and support networks in the schooling of children with disabilities**

The interviewees spoke extensively about the role of mothers in caring for their children to enable schooling. All of the interviewees stopped working after their children's diagnoses and dedicated themselves exclusively to them, becoming their primary caregivers. They are the ones who organize the children's routines, accompany them to therapies, school, or school transportation, and take an active stance in the fight for their children's rights:

*I was always following up, they kept saying there were no places [at the school], and when I followed up, I even went to a council, to a police station. [...] then in the afternoon, they called me, saying there was a place (M1).*

*Because usually, I already call and reach out to the supervision<sup>8</sup> to say that the elevator is broken, and he's not going to school because of that (M2).*

*They [the school] ask for participation regularly, and when I can, I also go. I've been on several field trips they've had (M3).*

The central role of mothers in caring for children with disabilities is highlighted in the literature. Factors such as stress and overload, the abdication of professional and academic life to dedicate themselves exclusively to their children, and the almost exclusive responsibility of mothers for caregiving are described (Almohalha et al., 2021; Ignácio & Uhmman, 2021; Rabelo & Magalhães, 2021).

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<sup>8</sup>It refers to the supervision of the Board of Education of the Municipal Department of Education.

The interviewees do not have others in their support networks with whom they can share the care of their children with disabilities. They mention being able to rely on the support of health services and, primarily, on other mothers of children with disabilities.

*The only support I've had during these 5 years was at LARAMARA<sup>9</sup>. There, they also provide social support for the family and the child's caregiver. It was through them that I received guidance and enrolled him in school, as he needed to have that school experience, interact with other children, and live through this because it is his right (M2).*

*We talk among the mothers at the rehabilitation clinic, exchange experiences. We chat, clear each other's doubts, try to help in any way we can, and that's how we keep going (M3).*

Ignácio & Uhmman (2021) demonstrate the need for social support and listening spaces for families. Cabral et al. (2021) emphasize the importance of developing programs with multidisciplinary teams for the creation of support groups and other resources that consider the uniqueness of the children. Almohalha et al. (2021) mention support groups aimed at promoting information, workshops, therapeutic services, and recreational activities for children and adolescents, as well as their families. Rocha et al. (2022) also highlight the role of the occupational therapist as a facilitator in building support networks both inside and outside of school.

## **Discussion**

The interviewees report benefits from the process of including children with disabilities in regular schools, although they point out difficulties in exercising the right to education, from enrollment to the realization of participation in the school environment. The opportunities for dialogue with the school are varied but depend on the active involvement of the mothers of children with disabilities in their creation. Many of these dialogues were mediated through negotiations or even formal complaints against schools to municipal management authorities. The relationship between the school and families needs to be reconsidered, which aligns with Cabral et al. (2021), who state that the school must be attentive to the different family dynamics, and the family must collaborate with the school to help promote an environment rich in resources and activities for different teaching and learning processes.

Although the specific literature in the field recognizes the importance of the family in the learning and schooling process of students with disabilities (Rocha et al., 2022; Silva, 2022), the interviews revealed that, in relationships with schools, the family's knowledge is not always recognized, which had to be actively built by the interviewees.

The impact of schooling for children with disabilities, as noted by the interviewees, was seen in increased socialization of their children and in the organization of family routines. Although the interviewees did not mention impacts in terms of content learning, this is not the sole function of the schooling process, according to Article 205 of the Federal Constitution (Brasil, 1988):

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<sup>9</sup>An institution specialized in the rehabilitation of people with visual impairments.



Education, a right for 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, their preparation for the exercise of citizenship, and their qualification for work.

Thus, the school plays a central role in the formation of both the person and the citizen. The involvement of mothers in the pursuit of their children's rights and in the creation of more inclusive spaces, as well as their fight to ensure their children's equal participation in field trips, classrooms, and all other activities, aligns with the goal of fostering citizenship formation for both mothers and their children. In this stage of childhood, children begin to understand access to education as an opportunity to be present and participate, as well as the desire to attend a school they like, or come to like, as the mothers describe.

However, this does not mean that the teaching of content should be neglected in favor of socialization, but rather it reinforces the importance of considering all aspects of school participation and learning in educational projects. Data from the United Nations Children's Fund (UNICEF) show that, globally, 42% of children with disabilities are less likely to become literate or learn mathematical concepts, not because of clinical reasons but because of social conditions that limit access to quality education (United Nations Children's Fund, 2021).

It is important to consider the need for transforming attitudinal barriers within schools – one of the most frequently mentioned by the interviewees, alongside barriers related to housing accessibility and school transportation. This factor influences how families perceive schools. As Rocha (2007) points out, it is the responsibility of the occupational therapist to create spaces for dialogue and exchange between the community, families, educators, and students. These dialogues do not only occur in relation to specific knowledge about disabilities but also in the relational domain, addressing emotional and affective difficulties, facilitating the identification of the potentialities and needs of students with disabilities (Rocha, 2007).

A school that promotes the learning of children with disabilities and fosters their development as citizens can change how families perceive their children, enabling the construction of new possibilities for the future. This idea contrasts with what Ignácio & Uhmman (2021) propose, which is that when a family does not accept the diagnosis, school inclusion becomes difficult, as it is only feasible when the family accepts the diagnosis and the disability. Here, a different perspective is advocated, as the school is understood to play a potentializing role in helping families comprehend that students are more than their disabilities and limitations, becoming a space that allows all students to envision other paths, discover strengths, talents, and new forms of participation in the world. As Dessen & Polonia (2007, p. 26) remind us, “[...] the function of the school is to stimulate the student's potential, considering sociocultural differences in favor of the acquisition of knowledge and overall development”.

Another determining factor in the relationship between family and school is the need to enforce the rights of students with disabilities within school spaces. Despite laws and decrees, such as the LBI (Brasil, 2015) and the National Special Education Policy from the Perspective of Inclusive Education (Brasil, 2008b), families still report numerous barriers, both physical and attitudinal, encountered not only in schools but also in

accessing school transportation, territorial accessibility, and the right to access the city as a whole, indicating the need for progress in ensuring the right to the city so that the right to education can also be fulfilled.

Finally, the interviewees did not mention the social movements of people with disabilities as a source of support, including in the fight for rights, which differs from expected results. There is no contact with organized social movements that engage in struggles for public policies, rights, and better living conditions. The interviewees find support from other mothers of children with disabilities, creating a female support and exchange network that helps each other during difficult times, shares information, and expands their knowledge about possible actions, which aligns with the concept of interdependence presented by the Second Generation of the Social Model of Disability, which, according to the Oxford Languages Dictionary (Oxford University, 2022), is the quality of people or things relating to each other through mutual dependence, achieving the same goals via mutual support or reciprocal collaboration.

Fathers and other men in the family are not mentioned as sources of support, leaving the full-time care of children with disabilities to the mothers. This fact reinforces the dominant view that women should take on this role, especially when it comes to children with disabilities. It is necessary to question this assignment of the caregiving role to one person, who often sacrifices their professional and social life to take on the care of people with disabilities alone, without the support of other family members (Barbosa et al., 2008).

## **Conclusion**

This study sought to understand and analyze how families of children with disabilities perceive the impact of schooling on their everyday life. The mothers recognize and appreciate the strategies promoted by different schools in various regions of São Paulo to facilitate the participation of students with disabilities, but they also identify barriers, particularly attitudinal ones. The mothers of students with disabilities play an active and central role in fostering dialogues with schools, advocating for rights, and creating a support network that assists other mothers of children with disabilities.

It was possible to observe a recognition, on the part of families, of regular schools as a space for the socialization of children with disabilities, as well as the impact of schooling on the organization of family routines.

It is hoped that the results obtained will help identify the necessary actions toward building more inclusive schools and cities for everyone, particularly regarding the deconstruction of attitudinal barriers experienced by students with disabilities and their families. It is important to highlight the prominent role that occupational therapists can play. Through intersectoral and interprofessional work, they can build support networks inside and outside of school, contribute to the continuing education of educators, identify the different needs and potentialities of students, and facilitate communication between families, students, and schools, enabling the creation of future projects and helping the school to become a transformative space for students, families, educators, and the community.

This research, although involving participants from four regions of the city of São Paulo, is a case study, and does not intend to demonstrate how the inclusion of people

with disabilities occurs throughout the entire municipality. Thus, it is suggested that further studies with a larger number of participants be conducted to map the situation of the inclusion of students with disabilities in São Paulo.

This study had the limitation of focusing specifically on students with disabilities and their families, with no educators interviewed. It also did not address other populations without disabilities who similarly face difficulties in accessing and participating in the school environment.

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Bianca Miyuki Nakamura original design of the study and the research project from which this article is derived, collection and analysis of data, writing and revision of the manuscript. Camila Cristina Bortolozzo Ximenes de Souza supervision of the research project from which this article is derived, supervision of data collection and analysis, drafting and revision of the manuscript. All authors approved the final version of the text.

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