






## Maternal conceptions about remote learning for children with autism spectrum disorder during the pandemic\*

Concepções maternas acerca do ensino remoto para crianças com transtorno do espectro autista na pandemia

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### ABSTRACT

**Objective:** to understand the challenges of remote learning for children with autism based on maternal perspectives. **Methods:** qualitative study conducted with 22 mothers from an association. Data collection involved participatory dynamics using the Comic Book Technique. French discourse analysis framework was used for material analysis. **Results:** the educational system's difficulty in addressing the uniqueness of children with autism had been an issue since their entry into school, and the pandemic exacerbated their exclusion. There was no adaptation to remote learning, and mothers chose to withdraw their children from school. The children's departure was ignored by teachers and school administration, and schools did not take responsibility for this population. **Conclusion:** the educational system was deemed inefficient in meeting the needs of these children during the pandemic. The lack of educational activities contributed to mental and emotional strain for the mother-child dyad and regression in the children's skills and behaviors. **Contributions to practice:** maternal narratives should be considered and addressed by education professionals in the development of special education protocols, to guide and optimize educational practices in public health emergencies. **Descriptors:** Education; Mother; Autism Spectrum Disorder; Pandemics; COVID-19.

### RESUMO

**Objetivo:** compreender as dificuldades do ensino remoto para crianças com autismo a partir dos discursos maternos. **Métodos:** estudo qualitativo, realizado com 22 mães de uma associação. A estratégia para gerar os dados envolveu dinâmicas participativas por meio da Técnica do Gibi. O referencial da análise de discurso de linha francesa foi adotado para análise do material. **Resultados:** a dificuldade do sistema educacional em lidar com as singularidades das crianças com autismo foi a realidade desde o ingresso na escola, e a pandemia acentuou a exclusão. Não houve adaptação ao ensino remoto, e as mães optaram em retirá-las da escola. A saída das crianças foi ignorada por professores e direção, e as escolas não assumiram a responsabilidade em benefício dessa população. **Conclusão:** o sistema educacional foi considerado ineficiente para atender às demandas dessas crianças durante a pandemia. A ausência de atividades educacionais foi responsável pelo desgaste mental e emocional para mãe/filho e pela regressão nas habilidades e nos comportamentos das crianças. **Contribuições para a prática:** as narrativas maternas devem ser consideradas e abordadas pelos profissionais da educação, para elaboração de protocolos de educação especial, para direcionar e otimizar as práticas educativas em situações de emergências de saúde pública.

**Descritores:** Educação; Mães; Transtorno do Espectro Autista; Pandemia; COVID-19.

## Introduction

During the coronavirus disease 2019 (COVID-19) pandemic, global health authorities imposed widespread lockdowns to minimize the spread of the infection and, consequently, control the number of illnesses and deaths<sup>(1)</sup>. The enormous impacts of the pandemic period forced both formal and informal sectors to suspend their activities, and the education sector was no exception<sup>(2)</sup>. We witnessed the greatest historical disruption in educational systems, with about 94% of the student population from over 190 countries and all continents experiencing the consequences of the closure of all learning spaces<sup>(3)</sup>.

With the suspension of all school activities, distance education was attempted as a means to ensure that this right was not interrupted during the pandemic<sup>(4)</sup>. For nearly two years, in-person learning was replaced by remote learning, requiring students, parents, and teachers to alter their daily routines to accommodate the new and unforeseen educational realities<sup>(5)</sup>.

Adapting to this mode of learning was difficult for all students, particularly for those with Autism Spectrum Disorder (ASD), who require specialized care and supports and services that are difficult to replicate in an online environment<sup>(2)</sup>. The existing educational disparities became even more apparent during this period, as the immediate need to switch to online teaching further reinforced the exclusion and systemic marginalization experienced by students with disabilities, including those with ASD<sup>(6)</sup>.

The pandemic highlighted the vulnerability of students with autism, as the educational measures adopted during this period were likely unfavorable for this population. Meeting educational needs at home, with little or no professional support, represented an additional burden and caused significant maternal distress<sup>(7)</sup>.

The pandemic was a challenging time for mothers who had to manage full-time childcare and deal

with their child's challenging behaviors, while being deprived of social, emotional, and psychological support resources and having to juggle multiple roles for which they were unprepared. As the focus shifted to the pandemic, less attention was given to disadvantaged groups, such as children with disabilities and their mothers, who were not prepared to manage online activities<sup>(8-9)</sup>.

The relevance of this work is grounded in the need to direct attention and discussions toward special education during times of pandemic and how this impacts the quality of life and health of the mother-child dyad. Thinking about and discussing this issue allows education and health managers to consider future possibilities and to develop and implement interventions aimed at making education more effective and inclusive, mitigating the negative effects of future public health emergencies.

In light of this, the following research question was raised: What is the perception of mothers of children with ASD regarding the challenges their children experienced with education during the pandemic? To address this, the study aimed to understand the challenges of remote learning for children with autism based on maternal perspectives.

## Methods

This is a qualitative study based on the Consolidated Criteria for Reporting Qualitative Research (COREQ). The research was conducted at an association located in a town in the state of Paraíba, Brazil.

The participants were 21 mothers and one grandmother (adoptive mother) of children with ASD who were assisted by the association, aged 22 to 72 years, who accepted the invitation from the institution's president to collaborate with the study, being selected by convenience. It was clarified that there would be no harm or penalty for participants who chose to withdraw from the research.

Inclusion criteria were established as follows:

being a mother of a child with ASD; having been a member for a period of two years or more; and being of legal age. Those who did not attend the association or who exhibited flu-like symptoms during the meeting period were excluded. During data collection, there were 22 families registered with the association, with no refusals to participate in the study.

The meetings were scheduled according to the mothers' availability and took place from May to July 2022, considering data saturation<sup>(10)</sup>, in line with the children's psychopedagogical care schedules, to facilitate participation. For the execution of creativity and sensitivity dynamics (CSD), the Comic Book Technique was used, a playful strategy that allows participants to express a daily situation through analogies with comic book images<sup>(11)</sup>. The comics used were from *Turma da Mônica*, available for free in PDF format on the website <https://arquivosturmadamonica.blogspot.com/>, and were printed in color by the researcher.

The CSD sessions took place at the institution itself and were recorded using an audiovisual recording system; the environment was arranged to ensure the comfort of the participants.

The mothers were divided into groups on different days, according to the schedule of their children's psychopedagogical care. After explaining the CSD stages and providing the comic magazines, participants were asked to represent the following guiding phrase through the images: The main challenges faced by your child regarding education during the pandemic period were... The mothers discussed the educational reality of their children with ASD, relating it to the comic book images. The session allowed for dialogue among participants and lasted an average of 58 minutes.

An activity was conducted only with the association's President, as she is the mother of a child with autism, to observe the understanding and internal consistency of the activity; however, this activity was subsequently discarded. The CSD sessions were transcribed in full, and the material was submitted to

participant validation the following week, increasing the credibility of the data.

For data organization, the empirical material collected was typed with information from the CSD sessions, the comic book images chosen by the participants, and the researcher's observational notes. French discourse analysis was used as the theoretical-analytical framework. Discursive *corpus* construction was achieved through maternal narratives and their association with the chosen comic book images, forming the discursive object. After repeated readings of the *corpus*, indicators of the analytical devices constituting the subjects' discourse were identified<sup>(12)</sup>. Paraphrastic, polysemic, and metaphoric processes were identified, enabling the relationship and analysis of discursive formations. This examination of statements characterized the mothers' discourses in terms of their ideological positions, relationships with other discourses, interdiscourse, and historical affiliation networks.

To ensure confidentiality and anonymity of the participants, they were identified by the letter P followed by an ordinal number (P1, P2, ..., P22). The research was approved by the Ethics Committee for Research with Human Beings at the Center for Teacher Education of the Federal University of Campina Grande under opinion 5,248,572/2022 and the Certificate of Ethical Appreciation Presentation 54377321.8.0000.5575.

## Results



The barriers to school inclusion for children with autism were already a reality for mothers before the pandemic and were exacerbated during this period. The children's challenging behaviors, the difficulties faced by education professionals in dealing with this population, changes in routines, and the laboriousness in adapting children with ASD were factors that hindered their education during the pandemic. The complete disengagement from educational

networks meant the loss of a support system composed of teachers, peers, social workers, and psychopedagogues, which had significant repercussions on the lives of children with ASD and, consequently, on their mothers.

After analyzing the discourses, considering the conditions of discourse production and the researchers' interpretations, two discursive formations were organized: "The Reality of School Exclusion for Children with Autism" and "Left Behind: Children with ASD Were Ignored During the Pandemic".

### The reality of school exclusion for children with autism

Although school inclusion is a civil right, mothers reported that "the lack of preparedness" of the education system to address the uniqueness of children with autism was a reality from the moment their child entered school, and the pandemic only exacerbated the systemic marginalization already experienced. In Figure 1, some narratives about the barriers faced for the school inclusion of their children are observed.

Comic Book Figures chosen by the mothers	Maternal discourses
	<p><i>I have been through so much struggle with the school that I could not even say. I did not even have time to get home before// they (referring to the school staff) would call to pick up (daughter's name) because she did not want to stay. They said that in class she just cries, does not stop, she does this or that... but actually, they are not prepared to deal with (daughter's name) (P2).</i></p> <p><i>I have suffered so much with the school, you know?! (Son's name) did not want to go, cried, did not want to stay there at all. The girls (referring to school staff) would call and say: come pick up (son's name), he does not want to stay, he is crying. I prayed a lot to God, talked to the administration, to the teachers, trying to find a way for him to stay in school. I saw that the school was not prepared to handle (son's name) (P3).</i></p>
	<p><i>Actually, the education system is not prepared to receive our children // nor are we parents, imagine the education system (P10).</i></p>

**Figure 1** – Challenges for the school inclusion of children with autism. Cajazeiras, PB, Brazil, 2022

Maternal narratives revealed that children with ASD were already facing significant challenges in school inclusion. Many difficulties were related to the child's own characteristics, which affected everything from their relationships and interactions with others to their language, posing a great challenge not only for teachers but also for the administration, staff, and even peers who shared the same environment.

Discursive fragments: *But in reality, they are not prepared to deal with (daughter's name) (P2)* and *I saw that the school was not prepared to handle (son's name) (P3)* represented the entirety of the participants' statements. The mothers considered that educational environments and edu-

cation professionals were not prepared for the demands required by school inclusion, and this hindered the integration of the children into the school.

The narrative: *Education system is not prepared to receive our children // nor are we parents, imagine the education system (P10)* indicated that the mother recognized that it was not only the school and/or teachers who faced difficulties in managing the child with autism. A child with any type of disability generated fear, uncertainty, and insecurity, which were present in the lives of families, who were also unprepared to receive them, making it a continuous process of acceptance.

The discourses indicated that discrimination against those who were different was a practice that was socially reproduced, perpetuating concepts and practices unfavorable to the inclusion of individuals with any type of disability. The statements highlighted the rejection of those who did not fit the desired behavior standards. The comic book figures also demonstrated that the inclusion of a child with ASD in the educational context was a source of strain for the mother/child dyad.

Proper training, a change in the perspective of educators, effective resource allocation, and efficient public policies are essential adjustments needed to make education more inclusive for students with

disabilities and to address the challenges this issue has introduced to the classroom.

**Left behind: Children with ASD were ignored during the pandemic**

In this study, all the mothers stated that their children did not adapt to the remote education system and expressed dissatisfaction with the inefficiency of the education system in meeting their children’s needs, which had negative repercussions for the entire family. Figure 2 presents some narratives referring to education during the pandemic.


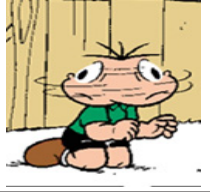
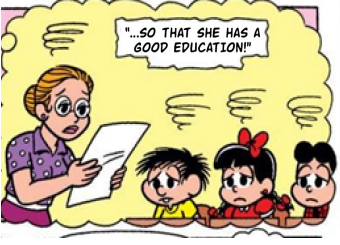

Comic Book Figures chosen by the mothers	Maternal discourses
	<p>(Son’s name) did not have access to the online system; he did not accept online classes. This Monica here (referring to the figure) is me running after (son’s name) to get him to look at the phone, and he would not take it; I went crazy, but there was nothing I could do // Then I went to the school and said: look, it is useless for him to stay... because it is not working, he does not want it. In 2020 and 2021, (son’s name) had no access to education (P4).</p>
	<p>It was 2 years without any engagement. The school did not offer anything beyond online classes for (son’s name). They conducted lessons as if he were like the other students, but he did not even look at the phone or understand anything. // I withdrew him from school, and he had no educational engagement at all (P6).</p>
	<p>(Son’s name) could not attend online classes. In the first year, the teacher did not adapt to the remote system; she could not teach. It was hard! In the second year, there was another teacher; they were more adapted to online teaching, but (son’s name) could not concentrate, did not do the tasks... he could not! There was no way he could stay still in front of the computer; in fact, he still does not. He got agitated with the children talking at the same time, with the noise of the classroom. So, I withdrew him immediately; I think it was for the best! The school actually left him behind! (P10).</p>
	<p>(Daughter’s name) did not adapt to the online mode. To start with, she did not even want to wake up to attend classes. When she did wake up, she would not look at the phone, she could not stay still, constantly running around the house, and I was very, very worried. She spent 2 years inactive and regressed in every aspect... Imagine a child with autism who, in addition, has an IQ below average, spending 2 years with no stimulation; the disruption was significant! This little doll (referring to the figure) is (daughter’s name), making a fuss to avoid attending classes (laughs); to avoid stressing me out, I withdrew her from school immediately (P16).</p>

Figure 2 – Maternal perception of remote learning for children with autism during the pandemic. Cajazeiras, PB, Brazil, 2022

Through the choice of comic book figures, it was observed that educational issues were arduous to manage and caused mental and emotional strain for both mother and child. Two important characteristics of autism were hypersensitivity and poor response to changes, and online learning disrupted daily routines. This triggered maladaptive behaviors in children and increased concerns, anxieties, and sadness among mothers. The metaphor used in the testimony: *I was going crazy, but there was nothing I could do...* (P4) described how the situation was difficult, challenging, and highlighted the frustration due to the inability to change the situation.

Due to the children's lack of adaptation to remote learning, all participants chose to withdraw their children from school, as they could not see satisfactory results with this mode of education. The mothers reported that the withdrawal of the children from school during the pandemic was ignored by teachers and school administration; that is, schools did not take responsibility to meet goals benefiting the autistic population, resulting in maternal sadness and disappointment.

It is important to note that, prior to the pandemic, 71% of the children in the study were enrolled in school and 29% in daycare centers. This means that all were involved in an educational setting with daily routines and interactions with peers and teachers, which supported their psychosocial, cognitive, motor, and sensory development. From the beginning of the state of emergency in March 2020 until the completion of data collection in October 2022, all the children had no access to schooling.

The metaphor: *...The disruption was great!* (P16) referred to the repercussions of the lack of school and stimuli during the pandemic. The mother's concern focused on the regression observed in her daughter and highlighted the importance of school for the child's development.

Other narratives emphasized the importance of the school environment for the children's development and how the absence of these activities caused

harm in various areas: *The lack of school harmed (child's name) a lot. I imagine that if the pandemic had not occurred, he would have made some progress* (P6). *With the lack of school, (child's name) regressed a lot... Social interaction is crucial for their development // He [referring to the child] listening to and repeating what others say, and interaction among children, is very important. Without it, he regressed significantly—truly a lot* (P15). *The lack of school was very difficult for (child's name). Online classes and the closure of the school brought a huge social loss* (P21).

Most participants agree that the school closure led to a regression in social communication skills due to the loss of socialization opportunities. Many of them report that there was a need to "catch up" on social skills after the pandemic ended.

## Discussion

This study was developed considering the perception of mothers regarding the difficulties faced by their children with ASD in relation to education during the pandemic period.

The arduousness in school inclusion for children with ASD are not only related to the right to attend school but also to the conditions provided to meet the special educational needs, ensuring progress and retention of this group in the educational system. At times, educators may not feel prepared for the demands posed by children and the peculiar characteristics of this population, such as difficulties in relating and communicating, following social rules, and adapting to new environments. Additionally, maladaptive behaviors and repetitive, stereotyped movements, which vary among people, require adaptations of traditional teaching methods<sup>(13)</sup>.

With the creation of public education policies for people with disabilities, schools are committed to addressing human diversity, requiring adaptation to the individual needs of students and avoiding the exclusion of those with special needs. This paradigm shift entails the deconstruction of rigid educational models<sup>(14)</sup>.

To work from an inclusive perspective, it is ne-

cessary to recognize that it is not only about organizing educational support but also about promoting an environment that encourages empathy and helps students develop, creating a place that fosters their learning<sup>(15)</sup>.

Inclusive education does not aim to transform schools into social services, disregarding their role in promoting new knowledge. However, it is essential to acknowledge that the right to education belongs to everyone. Therefore, it is up to all involved to seek alternatives to prevent exclusion and discrimination, regardless of the political, health, or any other context. Considering the complexity of the pandemic period, it was necessary to provide support to teachers to assist them in building inclusive pedagogical practices, as they were also unprepared to handle this situation<sup>(15)</sup>.

It is necessary to emphasize that, in the pandemic scenario, educators also faced significant and new challenges. They had to maximize their social and digital skills and adapt pedagogical practices to the virtual environment to maintain contact with students or their families. They had not been trained to manage virtual classes, which led to adaptation difficulties, and dealing with students with special educational needs was even more challenging<sup>(3,16)</sup>.

When referring to remote learning, mothers used paraphrasing of non-adaptation, which was present in all narratives. This reveals that providing education through digital means without proper adaptations leads to unfair discrimination, as it fails to reach populations already in vulnerable situations. From the statements, it is evident that the educational crisis caused by the pandemic only exacerbated the exclusion that was already a reality for individuals with autism, indicating that it is part of the interdiscourse.

The target audience of special education faced a double challenge: the first was related to historical conditions for ensuring inclusion in the schooling process, while the second emerged from the pandemic and pertained to the challenges of ensuring learning and development for this population in remote schooling<sup>(6)</sup>.

The result of our study is consistent with findings from other researchers indicating that people with disabilities and their parents faced difficulties participating in online classes. Children were unwilling to participate, and many experienced challenges adjusting to distance education. Remote learning requires a certain level of ease and familiarity with technology, sustained attention, motivation, organization, and cooperation, which are specific challenges for students with ASD<sup>(17)</sup>.

Considering the conditions under which the discourse was produced, it is important to highlight that the schools where these children were enrolled had specialized educational support. This support identifies, develops, and organizes pedagogical and accessibility resources that minimize barriers to the full participation of students, taking their specificities into account. Despite the presence and operation of specialized educational support, it is clear that remote schooling fell short in adequately serving people with ASD.

The findings of this research align with the literature, which indicates that during the pandemic, students with disabilities, particularly those with ASD, were deemed 'unteachable' due to inadequately adapted study materials, learning difficulties, and emotional, behavioral, or physical challenges that hindered their ability to learn<sup>(16)</sup>. The mothers' narratives are filled with sadness and a sense of failure and reflect the pandemic's impact on their mental and emotional health and the development of their children.

Some parents of children/adolescents with ASD acknowledge that the interruption of educational services caused their children to experience negative behavioral changes, including regression in various skills, increased or new maladaptive behaviors, and heightened mood symptoms<sup>(18)</sup>. The lockdown during the pandemic significantly impacted sensory-motor development, cognitive skills, sleep, behavior, and social interactions in about 50% of children with special needs<sup>(19)</sup>.

The school plays a significant role in the lives

of people with disabilities, as it represents a place for emotional, physical, cognitive, relational, and resilience development, as well as cultural and social awareness. Consequently, the interruption of these services brought psychological, emotional, social, and academic repercussions and increased the anxiety levels of this population<sup>(9,16,18)</sup>.

## Study limitations

The research was conducted specifically considering the perception of mothers of children with autism regarding their children's education during the pandemic within a single association. To understand the phenomenon more comprehensively, it is necessary to conduct studies in various institutions and include mothers from different socioeconomic contexts. Such studies could reveal differences in maternal perceptions.

## Contributions to practice

It is important to highlight the significance of discussing and strengthening the literature on the repercussions of the COVID-19 pandemic on the education of atypical children. Reflecting on and discussing maternal experiences allows for a better understanding of how support networks functioned during the pandemic, aiming to mitigate the negative effects of future public health emergencies.

The information obtained from maternal narratives can inform the development and implementation of educational protocols to minimize the exclusion and invisibility of individuals with ASD, which resonate in situations of neglect and social rejection.

## Conclusion

The mothers of children with autism considered that the educational system was inefficient in meeting their children's needs during the pandemic period. The lack of adaptation to remote learning was

responsible for mental and emotional strain for the mother-child dyad and for regression in the skills and behaviors of children with autism spectrum disorder, affecting their quality of life.

## Authors' contributions

Conception, analysis and interpretation of data, drafting of the manuscript, relevant critical revision of the intellectual content, and final approval of the version to be published; responsibility for all aspects of the text in ensuring the accuracy and integrity of any part of the manuscript: Teixeira OFB, Pessoa VLMP, Quixadá LM, Silva JWM, Miranda KCL.

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