

# Impacts of family neglect on the acceptance of autistic children: teachers' opinions

## Abstract

ASD is made up of stigmas, prejudice, and social segregation, which directly impact the family's relationship with the autistic child. The non-acceptability of the diagnosis by the parents causes the relationship between them to be impaired, and consequently, there is no promotion of quality treatment for the child. In this way, their quality of life and their interaction with other means of coexistence, such as school, which is of great importance in children's cognitive and social development, are compromised. Thus, the objective was to identify the challenges encountered by teachers in the teaching-learning process and to evaluate whether the problems identified are related to the disorder itself or whether how the family relates to these children influences this scenario. To this end, a study was carried out through a bibliographic survey and a collection of teachers' testimonies about the problem addressed.

**Keywords:** school, bibliographic survey, learning

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## Introduction

Autism spectrum disorder is one of the currently most well-known conditions affecting brain development, the cause of which cannot be stated for sure for a specific child. However, we can say that science currently brings us that autism is caused by a variety of rare genetic mutations, together with a common genetic susceptibility, in addition to environmental triggers in most cases.<sup>1</sup>

Autism is considered a disorder marked by qualitative impairment in socio-communicative development, the presence of stereotyped behaviors, and a restricted repertoire of interests, which should be identified as early as possible.<sup>2</sup> Thus, people who live close to children with suspected ASD must have enough information to have the sensitivity to perceive the suspected clinical condition. An aspect that is not extensively explored is the situation in which parents are absent and these children, often rejected, are taken care of by other family members, such as grandparents, uncles, or others who accept them with their atypical characteristics, with or without a diagnosis. This process can further hinder the socio-environmental development of a neuro atypical individual such as autistic people. In this regard, the emotional instability caused by changing caregivers is a challenge that can manifest itself through feelings of inadequacy and insecurity. Thus, the ideal would be for the new caregivers responsible for the child to know the inherent characteristics of the child and the disorder so that they promote a safe, supportive, and understanding environment.<sup>1</sup>

It is well known that ASD takes different forms in different individuals, as it is not a singular condition. This means that each child with ASD may present different social and/or behavioral difficulties in different aspects and situations, due to their spectrum and classification into support levels.<sup>3</sup> In 1977, some scientists traveled around England and identified all the pairs of twins in which at least one of the two was autistic, and analyzed that identical twins had ASD much more often than non-identical twins. This study leveraged the great role of genetics in the development of autism.<sup>4</sup> Given this broad theme, there is a lot of information and hypotheses, with an exacerbated dissemination of false and mistaken information about the concept, treatment, and causes of the disorder. In this way, the partnership between the family and the school is beneficial in several ways for the quality of life of children with ASD, since teachers spend

most of the day with their students in the educational environment and experience all their biggest deficits in terms of learning, self-regulation of their emotions, behavior and socialization.<sup>5</sup> Thus, in addition to contributing to the children's social and environmental adaptation process, they can include ways to disseminate truthful and easy-to-understand information to other typical and professional children.<sup>6</sup>

In addition, it is possible to imagine, in this context, the influence of the family socioeconomic dimension concerning the performance and direct search for appropriate treatments and resources available to these children in health and/or education institutions, since many families choose to reduce expenses to deal with the financial burdens necessary for treatment strategies.<sup>7</sup> Therefore, this is a strand that should still be explored due to the scarcity of studies focused on this theme and the need for protection and development involved in the entire educational process of an autistic child.<sup>8</sup>

Therefore, since the diagnosis of autism has an impact not only on the child but on the family and other people who live with this child, changes begin and are also reflected in their social environments, such as at school, for example.<sup>9</sup> Therefore, knowing the profile of the parents of autistic children regarding their child, through the perception of the teachers of their school and the impacts caused by a precarious relationship between them are essential factors to promote development and quality of life for these children.

## Methodology

This is a qualitative, descriptive, and exploratory study. The study population was composed of twelve teachers who teach autistic students from the 1st to the 5th year of elementary school, seven from a public school, and five from a private school, both located in the southeastern region of Minas Gerais. The municipality where the research was carried out has an estimated population of about 169,056 inhabitants in an area of 1,142.747 km<sup>2</sup>. The city stands out economically for agriculture, commerce, tourism, and industry, including the production of minerals and mineral waters.

Data collection was carried out through semi-structured interviews based on a previously established script with five open questions. The questions referred to the challenges encountered by teachers of

children with ASD resulting from family negligence present in their daily lives, in addition to strategies used by educators and initiatives that they believe should be taken by parents to better adapt to their children.

The interviews were recorded in audio form and transcribed maintaining the originality of the information. The interview was chosen because it is a method that allows depth in the face of points of view. The data were organized and analyzed by the content analysis proposed by Bardin. In qualitative research, content analysis, as a method of organization and data analysis, has unique characteristics, standing out for its focus on qualifying the participants' experiences and their perceptions about certain objects and phenomena. Based on the method proposed by Bardin, the data analysis was conducted in three distinct stages: pre-analysis, analytical description, and referential interpretation.

The pre-analysis took place simultaneously with data collection and involved the organization and initial reading of the material. In the analytical description phase, the empirical material was submitted to detailed readings, during which statements were selected for the construction of units of meaning, allowing the recognition of empirical categories. In the referential interpretation stage, there was an articulation between the empirical results and the theory, with systematic procedures that enabled the survey of indicators and the inference of knowledge. The study was approved by the Research Ethics Committee (CEP) under opinion No. 6,574,575.

## Discussion

In-depth studies of science on ASD have brought a lot of information over the years, which has resulted in strategies that can start even in early childhood and that parents and educators can use to support the development of these children. It is known that the first form of intervention for children with ASD is educational and behavioral and it becomes essential to develop collaborative and positive partnerships between family and school. Studies suggest that intervention practices with preschool children tend to generate more promising data than programs involving older individuals.<sup>10</sup>

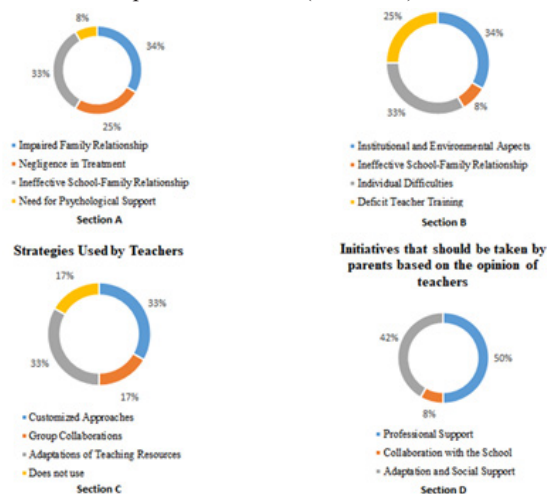
The particular characteristics presented by children with ASD often lead many mothers to withdraw from social life, in an attempt to avoid the stigma associated with their child.<sup>11</sup> The high level of dependence on family support and the lack of other forms of support generate feelings of anxiety, insecurity, and fears about the future condition of autistic family members, which ends up affecting the family as a whole.<sup>12</sup> Thus, the impaired interfamily relationship and the absence of psychological support for parents also proved to be significant barriers for the educators interviewed.

In addition, regardless of the treatment method used, whether it is Applied Behavior Analysis (ABA), speech therapy, hippotherapy, or another therapeutic strategy, it is necessary to have a properly qualified team for its implementation and a family willing to adopt the therapeutic strategies and engage in the treatment, to enhance the advances, whether in cognitive terms, social, behavioral, or even related to body physical structure.<sup>13</sup> However, the lack of adherence to the treatment offered to their children with ASD or even the lack of family engagement according to the needs required by the child is another example of negligence that affects the social and learning spheres in the classroom context.<sup>14</sup> The aforementioned study highlights the need for an integrated approach where families, schools, and communities work together to create an inclusive and supportive environment for children with special educational needs. In other words, families play a significant role in promoting self-

confidence, autonomy, and adaptability in children with special needs, helping them to face the challenges associated with their condition.

Consequently, the results obtained in the interviews were divided into four graphs (Figure 1), separated, respectively, by the themes:

- Influence of family neglect on the learning and socialization of autistic students at school (Section A)
- The greatest challenges faced by teachers when teaching their students with ASD (Section B)
- Strategies used by educators to alleviate the socialization and learning challenges of their autistic students (Section C)
- Finally, initiatives that should be taken by parents to better adapt their relationship with their child (Section D).



**Figure 1** The results obtained in the interviews.

Regarding the family's involvement with the autistic child, it is worth emphasizing the importance of co-parenting, since the unequal division of tasks generates an overload for one of the parents. Parallel to this, the lack of this family union affects the insertion of those responsible in the autistic person's reality and, as a result, he is more susceptible to helpless exposure, which can reflect negatively on his development.<sup>15</sup> It was possible to perceive, through the teachers' reports, that a good relationship between the family and the autistic child, based on the presence of parents at school and the development of welcoming practices and understanding of the uniqueness of the disorder, are fundamental for the child's school development, demonstrated in the excerpts below:

"... when parents don't see potential in their child... you ask what the abilities are and he can't perceive it either, the child has abilities but he doesn't realize it because he's still denying, you know, the child's condition" (Teacher 1).

"... I believe that he does have support, but I think he had to come and pick him up, he had to show up at school because he leaves by van. So, like, I don't know the family yet... I think this is essential, even in the student's emotional state" (Teacher 4).

"When parents... they don't understand their child and don't accept their child the way he is, regardless of what he has, this difficulty comes instantly, you know, so the negligence may be affecting the social level of the child who doesn't want to interact, the level of interaction between teacher and student" (Teacher 8).

For the proper development of a child with ASD, qualified health professionals must work in the areas of cognition, affectivity, and motor skills. However, the active and engaged support of the family is equally essential to ensure quality work and to maximize the benefits of treatment, which requires the collaboration of the family. However, three teachers also reported an association between the delay in the learning and socialization of these students and the negligence of parents in adhering to the treatment offered to these children. Some examples are listed in the following accounts:

"... it was a student who banged his head on the wall, I don't know if D. spoke or not, he hit his head on the wall, he hit his head on the floor. All this without the medication, the family did not accept the medication" (Teacher 2).

"... The mother, for example, doesn't tell the doctor... her exact behavior here at school... So the doctor can't prescribe the correct medication, or if he prescribes it, the mother decreases the medication, because either the child is more... She's calmer and the family thinks she's super apathetic, but she's there in that moment of more concentration, you know, of really being able to learn, the family goes and takes the medicine when she wants, the way she wants to do it. This is also being harmful here for us" (Teacher 7).

The school, as it is a diversified environment with multiple adversities, can help promote a more pleasant and welcoming environment for the child, as there is a variety of children with different characteristics. For there to be a good promotion and elaboration of different teaching strategies, it is necessary to have a good understanding of the child's needs, constant communication, and social and emotional inclusion. Thus, four teachers highlighted the importance of cultivating a good relationship with parents in everything related to the school and vice versa. When this does not happen, there is damage to the school development in social and cognitive terms of the child with ASD, according to the teachers, reported in the following excerpts:

"... Sometimes we refer students to a psychologist, to a speech therapist and there are families that end up not taking them, right? If we forwarded it, it is because we saw the need" (Teacher 2).

"... if the family does not participate, if the family does not... interacts with the school, this student ends up... not developing as we would like him to develop" (Teacher 3).

In addition, it is currently verified that there is a large gap concerning teacher training to deal with autism in Brazilian schools. The importance of training professionals able to work with students with ASD also corresponds to a new conception of school, in which there is legal equality of opportunities and educational equity.<sup>16</sup> It is possible to see these gaps in section C of Figure 1, where 17% of the teachers interviewed do not use any type of strategy to minimize the learning and socialization challenges of the children with ASD to whom they teach.

The current literature shows us that most teachers feel unprepared to deal with autistic students. The feeling of helplessness, frustration, and helplessness of teachers, associated with the fear of dealing with certain behaviors of the student seems to indicate a discredit in their capacities to adopt effective educational practices.

"... but I had never seen a severely autistic person, so on the first day I said 'My God, how am I going to work with him? Because I had doubts' in college, unfortunately, we are not prepared for practice. I had doubts about whether he understood me because I didn't know, I talked to him, but I didn't know how to talk to him" (Teacher 6).

Regarding the results obtained, there is greater knowledge of ASD among professionals from private schools, who mostly demonstrated knowledge of basic concepts that guide the disorder. Something very notorious in the speeches of some public school teachers was the fact that culturally they related autistic people to a common stereotype in popular beliefs, such as saying that autistic people "live in their world", and that all autistic people behave in the same way or reinforcing the fact that they are the same as other typical children. However, it is known that although autistic people share many characteristics with neurotypical people, they also have unique challenges and different ways of processing information and sensory experiences. In this way, ignoring these differences can lead to the absence of adequate support and a social setback, since autism is defended as a human condition and not a disease. This perspective challenges traditional views that seek to cure autism, promoting respect for neurodiversity similar to other social differences, such as race and gender, for example.<sup>17</sup>

"You have to see the child as a child like all the other children, all the other children. He can't see his son as different. Actually, he's smart, right?" (Teacher 1).

"In the case of L., he interacts very well with the other children. So, like that, I treat him like a normal boy" (Teacher 3).

Furthermore, by saying that it "treats as normal", there is an implication of an inadequate understanding of the disorder, as it suggests that normal features are only neurotypical features and that all features that deviate from this norm are considered abnormal. On the other hand, other teachers, when answering about the strategies used, said that this was variable due to the needs and interests of each child.

"Each child is different. There's no way we can get a rule. Every year we get one, it is completely different from the other. So, the first thing is for you to get to know the child" (Teacher 5).

"... I create strategies in the face of what he brings to me, in the face of what he needs, so I have a student, I have had a student where he needed to go out many times and what I did so that he was not just out of the room, so we presented things according to what he was interested in, This one specifically liked airplanes a lot, so he knew everything about airplanes, anything you asked about airplanes he knew. So I learned about all the 'Boeings', I did all the things so I could get to this child and when I managed to get to this child he asked me to make an airplane. So we made a very big plane and then we took classes inside the plane" (Teacher 8).

In agreement with what was obtained in this study, some results from other studies show that interventions through the teaching of social communication and knowledge about self-regulation for children with ASD and their parents are effective. The effects after the participation of parents and their children with ASD in the "Growing, Learning and Living with Autism" Group showed an increase in communication and knowledge of self-regulation compared to the control group of delayed treatment.<sup>18</sup> This means that addressing topics related to the child's specific goals and seeking treatment as part of the routine proved to be beneficial to interfamily relationships.

The importance of parental involvement in the success of interventions is essential, as they play a crucial role in the effective implementation of treatment, as they must apply the strategies learned in therapy sessions during interactions with their children daily. In addition, a specialized care plan in conjunction with treatment tailored to the child's needs provides parents with opportunities for support and a path forward in the expectation of getting to know and

understand their child better.<sup>19</sup> In line with this, the results of “Section D”, which deals with the initiatives that should be taken by parents in the opinion of teachers, brought in their vast majority the need for professional help for children.

“... parents need to see that that child needs accompaniment because if not, they cannot walk” (Teacher 4).

“... take him to therapy, follow him closely, follow him at home, talk to this child, stimulate him at home too... you have to go to fight too because standing still doesn't solve it” (Teacher 5).

“... The first step is for the professional to understand how to help and often it is not just a professional, the school concerning the autistic student does not walk alone, in addition to the parents it walks with psychologists, occupational therapists, and several... physical educator and so on... so you have to try to understand what your child needs with the help of these professionals” (Teacher 6).

Another issue to be addressed with autistic children is the negligence of parents with their children with autism traits, but who have not yet been diagnosed. This can happen due to the difficulty families have in understanding and adapting to the characteristics of their children's autism and therefore do not seek professional help. However, these same parents lack the support that is offered exclusively to families of children with a clinical diagnosis of autism.<sup>20</sup>

It is in this context that the health professional comes in, who can intervene in this scenario to contribute to the diagnosis, treatment, and family-centered care. The nurse establishes a link between the multi-professional team and contributes to the use of evaluation and intervention models. In addition, nurses are often the primary caregivers for children with autism spectrum disorder in hospital settings. They provide direct care, ensuring that the specific needs of these children are met during their hospital stay. Nursing staff must possess a high level of knowledge about the characteristics of ASD, which is crucial to recognize and address the specific challenges faced by children with autism.<sup>4</sup>

Basic Health Units, which represent a completely different health environment from a hospital, also play a substantial role in the diagnosis and awareness of autism. The Ministry of Health makes available in the “My Digital SUS” application the M-CHAT (Modified Checklist for Autism in Toddlers) scale, a tool considered the gold standard to help in early diagnoses of autism. The application of this scale should be carried out by nurses and doctors of the basic health unit as a screening for autism, classifying the child into one of four categories: no risk, low, medium, or high risk for autism. However, it is known that although the application of M-CHAT is mandatory in all childcare consultations in primary care, this is not usually the reality in primary health institutions.<sup>16</sup> The knowledge of health professionals about the scale and its applicability in practice is desirable but, in most cases, non-existent.

Thus, it is important to highlight that studies on the treatment of children with Autism Spectrum Disorder have emphasized the crucial role of multidisciplinary and inclusive approaches, involving various techniques to promote the bio psychosocial development of pediatric patients with ASD and neuro divergent conditions. However, despite requiring multidisciplinary treatment, autistic children need a personalized approach to clinical interventions, where different professionals work together on these specificities. The neurological manifestations and clinical treatment of ASD have shown a growing trend towards the need for continuous research and innovative therapeutic strategies.<sup>21</sup>

In the long term, the consequences of the lack of specialized and concerned attention can be negative. The autistic people of tomorrow may reflect contemporary trends of minimizing subjectiveness. They may have difficulty expressing themselves due to behavioral education methods that limit their subjective experiences.<sup>22</sup> Something very important, in this broader look to the future, would be to highlight the need to incorporate the perspectives of autistic individuals in clinical research. We must know how to give them a voice to ensure that the results of the research are relevant and beneficial to the autistic community, as this way they will be actively involved in the research processes and will be able to share real needs and experiences of autistic people.<sup>23–26</sup>

## Conclusion

The family plays an essential role in the life of an autistic child and their progress, so the acceptance of the diagnosis must occur for the better development of this child in all areas of their life. In the school environment, the role of teachers is fundamental in the initial identification, learning, and inclusion of autistic students. The training of these professionals is essential for this to happen, in addition to working together with the family and the multidisciplinary health team for a better adaptation to the school life of this child.<sup>27–30</sup> Training health professionals on the theory and application of M-CHAT is also of paramount importance, as it ensures that children with early signs of autism are identified as early as possible, enabling more effective interventions and significantly improving the development and quality of life of these children. This strategy not only benefits the child but also the parents and the health system as a whole. Well-trained professionals can help reduce the stigma and challenges that family's face in the diagnosis and intervention process. In addition, the lack of data regarding the prevalence and national incidence of people with Autism Spectrum Disorder highlights the need to develop research that evaluates the proportion of autistic children in the country, to facilitate the implementation of care for individuals with this disorder. This survey did not address economic factors that could prevent families from adhering to specific treatments. Therefore, further research should be developed to investigate this relationship that can limit access to the rights and benefits offered to children with ASD.

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## Conflicts of interest

The authors declare that they have no conflicts of interest.

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