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# Dealing with stress and intervention models in families with children with autism spectrum disorder

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Many academics working in the field of education have written about children with autism spectrum disorder (ASD) and its variant, specifically Asperger's Syndrome. This research aims to analyze and assess the studies and psycho-pedagogical actions developed to understand the actual experience of the families around the stress derived from the presence of a child with ASD. To this end, the strategies used by the families to deal with this situation should be assessed. This paper presents a systematic review based on an exhaustive search in key databases involving a total of 16 updated studies, published between 2010 and 2020, and a selection process that looked at results from five perspectives: causes of stress, strategies used by fathers, mothers, and siblings to manage the stress, more frequent intervention models, and the importance of the family-school relationship in coping with the reality and needs of these children.

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## Introduction

It is essential to work with the families of children with diversity from the educational and emotional perspectives since it is where “the main challenges of parenting emerge and where it is necessary to carry out the essential tasks of care; [...] Its proper performing constitutes the backbone for a good fitting to the rest of the spheres” (Yáñez, 2017, p. 271).

The present study digs into ASD that according to the DSM-V (American diagnostic semiology manual: American Psychiatric Association, APA) includes Asperger, classified within the category of Neurological Developmental Disorders. It is understood that these individuals have common characteristics such as difficulty in social interaction, poor communication skills, and stereotyped behaviors.

The family is essential both for physical and emotional protection (Suárez and Vélez, 2018). Furthermore, it is expected that, as the first socializing agent, the family teaches social norms and provides the necessary stimulation to the children to favor an emotional development that guarantees their personal and social identity (Guzmán-Huayamave et al., 2019).

Within the educational framework, an active and positive relationship between all educational agents and contexts is essential: the schools, the family, and the community (Simón et al., 2016). This relationship is crucial when the family has a child with a disability, whose experience is reported as frustration or in adaptation (Seva et al., 2016), especially in the case of ASD whose impact significantly affects the family life. Sometimes the lack of fitting between the family and the school contexts causes a sense of powerlessness in these families, who feel that they do not “fit in” an educational system, which they consider poorly adapted to the conditions derived from the presence of a child with ASD (Kendall and Taylor, 2016). The perceptions of different educational agents reflect that there are confusion and ignorance in relation to the implementation of truly inclusive quality education (Pérez-Jorge et al., 2020; Pérez-Jorge et al., 2021; Rose et al., 2021; Wearmouth and Butler, 2020). It should even be noted that some studies are showing that in the educational practice certain responses, which can be regarded as recommended for the majority, may be inconvenient for cases of special educational needs and disability (Williams-Brown and Hodgkinson, 2020).

It is common to discover that, from various instances, deficiencies in prevention, dedication, and intervention arise in cases of special educational needs that undoubtedly present greater social vulnerability (González Contreras et al., 2020). Currently, in the midst of a global pandemic, this fact seems to be exacerbated even more (Asbury et al., 2020; Chen et al., 2020; Schuck and Lambert, 2020). This is happening especially with autistic pupils, whose families use to receive insufficient and/or scarce care (Alhuzimi, 2021; Rios et al., 2020).

Catalano et al. (2018) highlighted the mental health problems of parents who take care of children with ASD. The reality of the cohabitation of the families with ASD children represents a significant risk for the psychological, physical, and social well-being of both, which generates adaptive problems for the families, as well as for the child. Along the same lines, Karst and Van Hecke (2012) explain that the effects of the difficulties suffered by the family have a reciprocal and negative impact on the child, causing a decrease in the effects of the intervention. However, most of the interventions in autistic pupils evaluate the child outcomes, disregarding the family aspects that influence the immediate or long-term effects of the therapy. It is not convenient to assume that the improvements derived from the interventions with these children will reduce the anguish or stress felt by the families, despite the fact that the time and cost of the intervention may add on top of the rest of the family problems.

Along these lines, Rodríguez (2006) points out an approach that includes the family in the process of accepting diversity and provides different strategies and alternative responses to traditional models of intervention centered on the person with a disability. The approach considers the family as one more agent on which to intervene to improve the quality of life of individuals with ASD; in this sense, it is stated that these interventions must be different from those proposed for the person with ASD, and must be aimed to developing and implementing effective programs for the families.

These programs are based on meeting the needs that these families present and that are mainly grouped into:

- Utilitarian needs such as behavior control, supervision of the child, the physical problems.
- Psychological needs such as receiving information and guidelines for addressing diversity.
- Instrumental needs such as time organization or handling their educational needs.

There are various types of programs that are based mainly on meeting the needs of each family; for this, it is necessary that the families get involved and that a continuous evaluation is made to check the needs that families present at any time. Examples of undertaken intervention programs are; orientation programs through interviews to get to know the families, their needs and concerns; inter-family relationship programs; family school programs, based on basic training, and home support programs to respond to the needs that arise in the family and at home.

It is necessary to inquire into the benefits that various intervention programs may bring to the families. Rojas-Torres et al. (2020) looked for evidence on the effectiveness of intervention programs for children with ASD based on the participation of their parents. Their results suggest the effectiveness of the programs developed and applied, highlighting the positive effect in terms of coping with stress. Similarly, Han et al. (2018) indicated that, although the permanent stress factors experienced by families can have negative effects on the empowerment of the family itself, the family abilities and the positive attitude of the parents can alleviate the negative effect of stress by using effective managing strategies. Other studies suggest that professional guidelines to support the mental health and well-being of caregivers should include the approach to realize their own perspective and their ability for solving problems in real-time (Catalano et al., 2018). More specifically, Ede et al. (2020) concluded that rational emotional family health therapy has beneficial and sustained effects on parental stress management. The value of a community-based, group-based parenting education program for families of children with ASD has also been highlighted in different studies. After participating in the program, parents reported reduced stress, increased knowledge of managing strategies, empowerment, and satisfaction (Milgramm et al., 2021).

This work focuses on the review of different studies and innovation projects for psycho-pedagogical intervention implemented in families with ASD children. We intend to know what family strategies apply to face situations derived from the presence at the home of a child with TEA, in order to assess their suitability and effectiveness in coping with stress.

## Methodology

For the elaboration of this study, the databases of Dialnet, Web of Science (WOS), and PsycINFO were used. To access them, the Punto Q portal of the University of La Laguna was used. The selected databases were considered based on the adequacy and

affinity of the publications with the field of education and educational psychology.

Regarding the restriction in the searching years, available documents from 2010 to 2020 were selected for two reasons: the first relates to ensuring that the study is up-to-date by including the most recent articles; in addition, before these years, no relevant articles were found focusing on the families of autistic children. It should be noted that in Spain, only after 2010 did a model of inclusion of pupils with autism begins to be developed, which prioritizes schooling in ordinary schools. According to data from the Spanish Ministry of Education from 2010 to the present, 83.5% of these students attend ordinary schools. Since 2010, the number of such students in ordinary schools has tripled; the percentage of such students in ordinary schools has increased by 218% from the 2010/2011 academic year to the present day.

Concerning the type of documents, no restrictions were applied, with the intention to obtain the largest number of papers related to the topic under investigation and thus, expanding the range of the study. The exclusion of doctoral theses or other types of non-peered studies could bias the results of the review, because of the so-called publication bias, which that by excluding certain studies, a systematic review will more likely overestimate the relationship between the exposure and the event of interest.

When performing the search on the above-quoted databases, various types of documents were found such as articles, books, dissertations, theses, etc. For this study, a total of 11 journal articles and five doctoral theses were finally selected. For the selection of the studies considered, the following inclusion and exclusion criteria were applied (Table 1).

A search was carried out taking into account the objectives and initial categories of the work related to the family intervention models and the action approach taken by parents and siblings to face the stress of educating and living with a child with ASD. In this sense, the need arose to know how the families who have children with ASD or Asperger's perform, what strategies are followed, whether having a child with autism in the family generates a higher level of stress, and, overall, to know whether there are studies or intervention models designed to help these families. Finally, the definitive scheme of sources selected and excluded according to the applied review was established, as reflected in Fig. 1.

Annex one of this work shows the documents used in this systematic review study based on the more relevant information for the categories proposed in this research.

Results

The results are presented divided into five subcategories; causes of stress in families who have children with ASD or Asperger; strategies applied by family members to cope with parental stress; strategies applied by siblings of children with ASD or Asperger's; models of family intervention and, finally, the family-school relationship.

To specify the percentage of documents that have been useful for each category, in particular, the main objective of each study

has been taken into account. In this sense, for the first category of analysis, 25% of the documents addressed this aspect. For the second and third categories of analysis related to the strategies used by both parents and siblings, respectively, the percentage was distributed as 25% for the second and 12.5% for the third. In relation to the fourth category of analysis, the percentage of documents identified was 25%. In the last category of analysis, the family-school relationship, the percentage of related documents was 12.5%.

**Causes of stress in families with children with ASD or Asperger's.** Tijeras (2017) states that parental stress arises from a stressor element closely related to parenting, such as the diversity of their child or behavior problems, among others. This generates a feeling of incapacity in the tutors that prevents them to apply strategies helping them balance or face the situation.

The stress suffered by the families of children with ASD may also be due to economic problems, the expenses for the care of these children are greater than in the case of children without ASD, which produces steady stress in the families. It should be emphasized that, normally, the mother spends more time with the child than other family members, even asking for a reduction in her working time and sometimes leaving her job (Luengo, 2016; Yáñez, 2017).

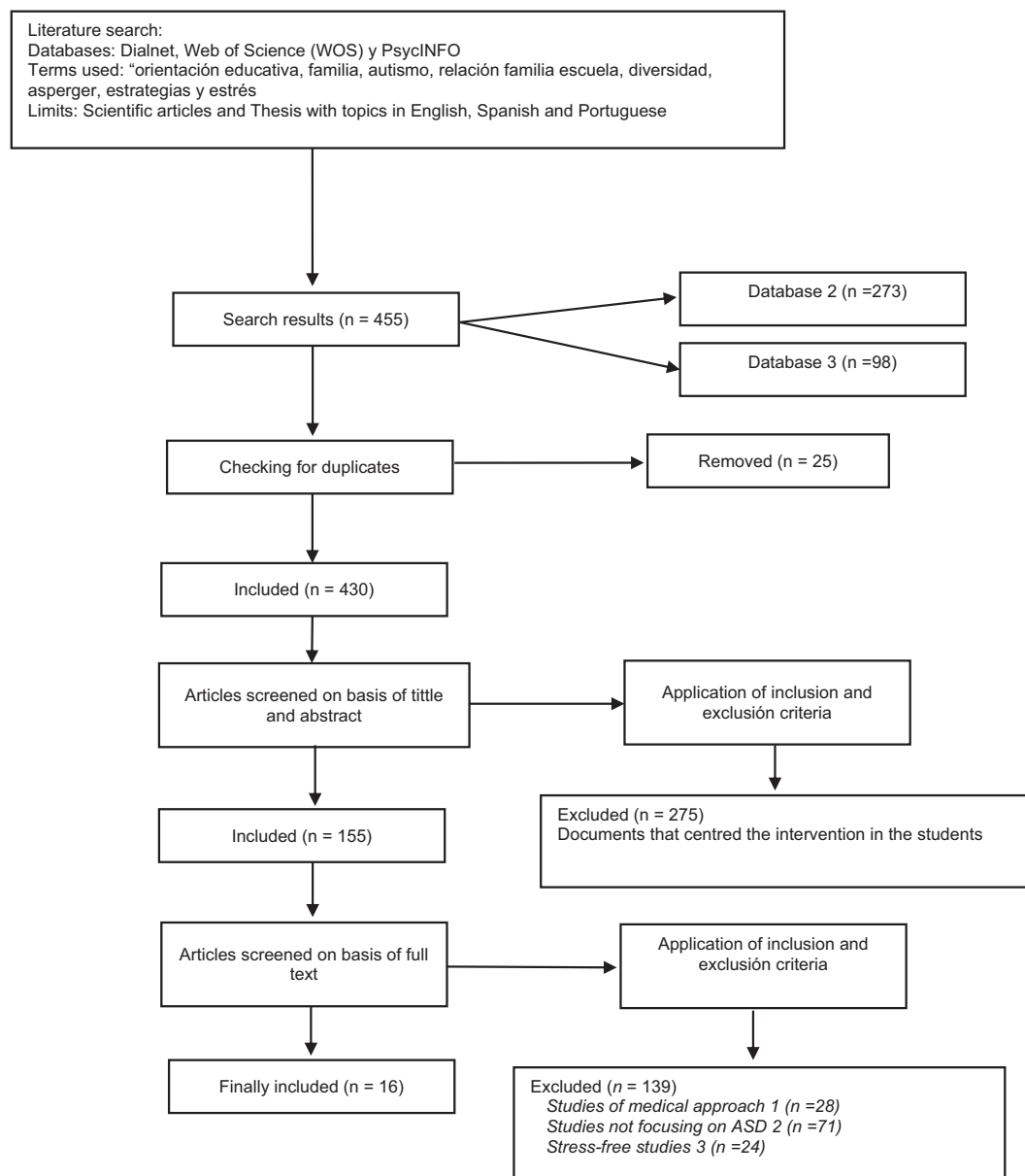
Another aspect associated with family stress is the child's diagnostic itself, i.e. when the parents receive this news there is an increase in stress levels. The family must face the challenge of adapting and managing the needs that these children demand (Pineda, 2012). This causes, as Luengo (2016) points out, greater family, marital, and sibling problems, since there is less time for him/herself and for the partner, thus generating various situations and emotions, among which the stress stands out. The child's degree of disability and the presence of non-adaptive or disruptive behaviors are also prominent causes of stress (Fernández et al. 2014).

**Strategies applied by family members to cope with parental stress.** Strategies are essential for families as they have easy success in coping with stress and assimilating the challenges of parenting. In this sense, Pozo and Sarriá (2014) confirmed that withstand the stress derived from this situation social support and coping strategies are required.

Focusing the study on the strategies mostly used by the parents, Luengo (2016) highlights that there are gender differences in terms of the strategies applied. Likewise, Luengo (2016) mentions the idea of Pozo and Sama (2014), that affirm that mothers use more adaptive and coping strategies. However, mothers found it sometimes more difficult to control the stress and sadness as compared to the men, who managed better.

Similarly, Luengo (2016) pointed out that the most popular way of coping with stress among parents with children with ASD is the use of therapeutic services and family support. Specifically, in relation to formal and informal social supports, it is essential for the family members to establish contact, through associations,

Table 1 Inclusion and exclusion criteria.	
Inclusion criteria	Exclusion criteria
Documents focused on ASD and families	Documents addressing other disorders
Documents on family intervention models in ASD students	Documents focused on a medical perspective
Documents on the strategies of families (fathers, mothers, and siblings) to cope with stress	Documents focusing on disorders other than ASD
Documents published in the last 10 years	Articles in languages other than those selected
Articles in English, Spanish and Portuguese	Documents older than 10 years
Documents in Open Access	



**Fig. 1 Selection process:** The process carried out for the search and selection of the different documents is shown. The selected search bases are detailed, as well as the total number of documents that appeared related to the subject in each one of them. After a review of the total number of documents, the repeated documents were eliminated, leaving a total of 430. This number was reduced by applying the inclusion and exclusion criteria, as well as different filters such as the reading of the title and the abstracts, finally obtaining 155 documents. Of the 155 documents, the inclusion and exclusion criteria filters were applied and 139 documents were eliminated. Finally, 16 were selected for the study.

schools, or clinics, with other parents who are in a similar situation. Regarding informal support, it is understood as the complementing element that families need to establish social contact with friends and family of a ludic nature in their free time. In addition, this contact also benefits the child since they can socialize in a different way.

**Strategies applied by siblings of children with Autism or Asperger's spectrum disorder.** There are very few publications focused on the importance that the siblings of a child diagnosed with ASD have in their life, or on the verification of the strategies used by the sibling without ASD in the family, personal or social dimensions, as well as to cope with the stress he/she may experience.

Talpachícat and Lucio (2019) pointed out that the siblings of ASD students use dysfunctional skills to a larger extent, that is, strategies based on social isolation, anger, self-harm, or opposition, followed by emotional strategies such as fear or sadness. In addition to other less frequently adopted, such as negotiation, problem-solving, adaptation, etc., as well as scarce self-criticism.

Talpachícat and Lucio (2019) observed that the problems suffered by these individuals normally are directly related to the applied strategies. Problems such as disobeying parents, challenging adults around them, self-harming, depression, or fearing the school failure or the family problems, show that the strategies used are not enough to cope with stress. Siblings have addition in their childhood an increased responsibility, as mentioned by Solomon and Chung (2012) in their study on the idea suggested by Yáñez (2017) and Luengo (2016), because they spend more

time with their sibling with ASD to help him/her to develop his affective, communicative, social, etc. side, even becoming second caregivers of these children.

**Families and intervention models to cope with stress.** There are many studies focused on direct intervention on children, leaving aside the needs of parents (Yáñez, 2017). In relation to the existence of new therapeutic approaches for families, Mindfulness appears, with positive results for the health of the parents with ASD children in many investigations carried out by different authors between 2006 and 2013, included in the work from Ruiz (2015). A prominent study carried out in 2006 by Singh and other authors on four parents who had a child with autism demonstrated how a program, focused on guiding these parents to know how to interact with the child, reduces stress levels.

Other resources to help these families are family therapists with functions such as: providing basic information about ASD; identifying the challenges in front of the diagnostic; designing a therapeutic program for the family and the child with ASD and helping the family members in understanding their emotions and the changes they face (Solomon and Chung, 2012).

**Family-school relationship.** Communication and compenetrating well in the family-school relationship benefits all those involved in the educational process that is activated with the aim of both educational agents.

In a study by Silva et al. (2019), it was concluded that teachers require and ask for more help and participation from the family side because its participation must be strengthened to favor the social life of ASD students. Social isolation arises more from society itself than from the incapacity of the child and, unfortunately, this begins in the family on the grounds of the fear of rejection.

However, the main difficulties faced by both systems to cooperate are based on knowledge and experiences. This means, according to Moschini and Schmidt (2017), that families can become experts and refuse to participate and confront the educational center, with the consequent difficulty in the interaction between teachers and families. However, as Moschini and Schmidt (2017) point out, the school should not become just an actor that provides information to family members, it should also be considered as a body that needs and must constantly learn, which benefits all the parts involved.

## Conclusions

As general results, several authors agree that the strategies mostly applied by families are adaptive in the mothers and avoidant in the fathers. However, in turn, they show that mothers have more difficulty coping with stress than fathers. In relation to the last aspect mentioned, there is not much information that allows guaranteeing this statement, however, it is known that the role of the parents, normally, is in the background, with the mother being the main caregiver agent for the child.

According to the presented argumentation, the vision of Rodríguez (2006) stands out. He believes that these families really need to be supported as a direct agent of intervention since they are more likely to suffer from stress, a condition that negatively affects the family and the child with ASD, also influencing the social and inter-family relationships.

Regarding the strategies applied by siblings with typical normal development, those that are dysfunctional, such as social isolation, self-harm, opposition, or anger, appear more frequently. Strategies of a functional nature, such as problem-solving, adaptation, negotiation, understanding, etc., are less common.

After carrying out this study, we can conclude that it is necessary to expand the investigations since it became evident that there have been little resources dedicated to these families, aiming to cope with the different situations that generate stress. It is pertinent to recognize the limitations of this work in relation to the databases used to find a variety of existing studies relevant for the subject. It was difficult to find enough papers focused on a topic as important and relevant as the one proposed in this work. We must also explain that the studies selected, despite not having the format of articles, meet sufficient quality criteria because they were evaluated and qualified with Cum Laude and were projects supported by research institutions subject to competitive evaluation processes.

From the selected articles, it can be inferred that stress-generating factors are multiple and can occur in all areas of life (economy, family, diagnosis, diversity, degree of disability, self-perception, etc.). The strategies applied by parents differ in terms of gender and the role of siblings seems essential to improve the development of ASD students in aspects such as communication and social interaction. Likewise, it should be noted the great impact that family intervention programs play to reduce stress levels, as well as the role that the family-school relationship plays in favoring the inclusion of ASD children, avoiding their social isolation.

## Data availability

All data analysed are included in the paper.

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## Author contributions

The authors contributed equally to this work and jointly supervised the work.

## Competing interests

The authors declare no competing interests.

## Ethical approval

Approval was obtained from the University de La Laguna ethics committee. The procedures used in this study adhere to the principles of the (Declaration of Helsinki). The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of CEIBA (protocol code 2021-0462 approval date: 13 April 2021).

## Additional information

**Supplementary information** The online version contains supplementary material available at <https://doi.org/10.1057/s41599-021-00988-3>.

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