Acta Psychologica 254 (2025) 104786

Contents lists available at ScienceDirect

Acta Psychologica

journal homepage: www.elsevier.com/locate/actpsy

Parenting a child with Autism Spectrum Disorder: A comprehensive analysis of family needs

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ARTICLE INFO

Keywords:
Autism Spectrum Disorder (ASD)
Family needs
Family support
Parenting

ABSTRACT

This study explores the perceived needs of families with school-aged members diagnosed with Autism Spectrum Disorder (ASD) in the Community of Madrid, Spain. Using a non-experimental, mixed-method design, the research assessed key needs across various dimensions, including information, family and social support, financial assistance, caregiving for the member with ASD, professional support, and community services. The results indicate that families experience significantly elevated needs, with information and educational support emerging as the most critical. However, no statistically significant correlations were found between the level of dependency or the age of the member with ASD and the overall family needs index. Additional qualitative analysis revealed that families prioritize access to adequate educational and professional resources, along with emotional and social support. These findings highlight the urgent need to develop inclusive policies and comprehensive support strategies to alleviate the burdens faced by families caring for individuals with ASD.

1. Introduction

According to the Asociación Americana de Psiquiatría (2013), Autism Spectrum Disorder (ASD) is classified as a neurodevelopmental disorder that typically manifests in early childhood. The primary characteristics of the disorder are based on the presence of persistent difficulties in social communication across various contexts, along with a range of restrictive and repetitive patterns of behavior, interests, or activities. Additionally, ASD can be categorized into three levels of dependency, with sensory processing disorders frequently co-occurring at each level (APA, 2013).

The diagnostic process for a child with ASD can trigger a wide range of emotions in the family receiving the diagnosis, such as sadness, fear, or uncertainty. This experience can become stressful or even devastating for some families, especially in terms of the ideals and expectations they previously held regarding their children's future (Ráudez et al., 2017). Furthermore, the uncertainty regarding the possible progression of the disorder may lead to manifestations of pessimism and negativity within families, which, in many cases, result in a significant reduction in the effectiveness of therapies applied to children with ASD (Russell & Norwich, 2012). These emotional responses can have a profound impact on various areas of the individual's development, such as their education (Chaidi & Drigas, 2020). Additionally, this emotional burden tends to be exacerbated in cases where families lack opportunities to share their feelings with others, due to widespread negative societal perceptions about disabilities in general and ASD in particular (Marriott et al., 2022; Villavicencio-Aguilar et al., 2018).

After parents of a child with ASD cope with the diagnosis and undergo a process of acceptance, studies by Olsson et al. (2015) and Maciel and Pereira (2020) indicate that families experience a significant emotional impact, which can lead to a modification of the usual family dynamics and structure, as well as the roles of each family member (Smith & Anderson, 2014). It has also been demonstrated that this type of impact can have severe consequences for both the parents' marital relationship and their social interactions (Anchesi et al., 2023; Befi et al., 2023; Chan & Leung, 2020; Downes et al., 2021).

Nevertheless, contrary to this situation, other research suggests that, after initially facing this stressful scenario, families are able to adopt strategies that enable them to cope with adversity more resiliently, ultimately resulting in a strengthening of the bond between family members (Dilleggi et al., 2019).

Furthermore, it remains important to consider the effects of the elevated levels of stress within the family dynamics of children with ASD, which are significantly higher than those found in families facing

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https://doi.org/10.1016/j.actpsy.2025.104786
Received 10 October 2024; Received in revised form 5 February 2025; Accepted 6 February 2025
Available online 12 February 2025
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other forms and types of disability, or in families with neurotypical children (Hayes & Watson, 2013; Iadarola et al., 2019; Valicenti-McDermott et al., 2015). Additionally, it is worth noting that the fact that family members of children with ASD often assume the role of permanent caregivers can limit their life opportunities, including the ability to obtain and maintain dignified employment, which is crucial for ensuring a good quality of personal and family life (Hill et al., 2015).

A review of the literature indicates that families of individuals with Autism Spectrum Disorder exhibit multiple needs across various dimensions of their family dynamics, which are primarily related to the need for information and support regarding their child's diagnosis (Rabba et al., 2019). In this regard, it has been determined that families often feel deeply disoriented after receiving the initial diagnosis (Martinez et al., 2018), which is attributed to the lack of immediate and useful information about the medical and educational services necessary to effectively support individuals with autism (Bejarano-Martín et al., 2020). Moreover, in terms of family and social support, there is a clear need to share experiences and opinions with other parents in similar situations. This highlights the importance of having opportunities to exchange advice and personal experiences, thus facilitating learning through the experiences of others (Cañete et al., 2018; Henao & Amariles, 2021).

Based on the findings from the review of the scientific literature, it can be concluded that the main needs expressed by families with children with autism are concentrated in three key areas. First, there is a notable lack of knowledge about the disorder, which affects how families perceive autism and limits their ability to seek the necessary support. Second, families face the social stigma associated with disability, which not only impacts their emotional well-being but also hinders their integration into the community. Lastly, significant difficulties are observed in families' access to essential services to address their children's autism-related needs, further exacerbating the challenges they typically face. A deep understanding of the needs of families of individuals with ASD will enable the promotion, development, and implementation of strategies and resources that address education on Autism Spectrum Disorder as well as improve access to support services, among other areas (Papoudi et al., 2021).

In addition, regarding the financial needs of these families, authors such as Abadia and Torres-Lista (2019) note that caring for a child with ASD can involve significant expenses related to specialized therapy and education services or access to clinical, healthcare, or social support services. The study conducted by Rogge and Janssen (2019) determined that the financial burden is much higher for families or individuals with ASD compared to those with other types of disabilities. Moreover, it was estimated that the greater the dependency level of the person with autism, the higher the financial burden assumed by the family.

The need related to caring for the family member with ASD is another highly significant concern expressed by this group of families. The study by Cañete et al. (2018) reveals that families who reported having adequate professional and institutional support for caring for individuals with ASD experienced a higher quality of life compared to families lacking such support. Similar results were found in the studies by Hodgetts et al. (2015) and Henao and Amariles (2021), where families reported significant difficulties in finding external caregivers, outside of the family system, to assist them in raising their children with ASD, which had a notable impact on family dynamics. As a result, most parents often find themselves compelled to assume the role of the primary and permanent caregiver, a reality that leads to a significant psychological burden for the individual taking on this role, highlighting the urgent need to implement assistance programs to alleviate pressure on these families (Kamati et al., 2021).

Regarding the dimension of professional support, Crane et al. (2018) emphasize the lack of emotional support provided to families by professionals specializing in the care of individuals with ASD (such as doctors and/or teachers) and how this undermines the family-professional relationship. For this reason, families encounter great difficulties and obstacles when trying to find suitable resources for their children, where they can not only receive comprehensive responses to their needs but also experience compassionate care from the professionals responsible for these services. Inadequate care from professionals attending to individuals with ASD and their families, or deficiencies in the services provided, especially in the educational field, have become one of the most significant sources of family dissatisfaction (De la Torre et al., 2018).

Based on these dimensions of family needs, the objective of the present research was formulated through the following questions: What are the current needs and situation of families with school-aged children and adolescents with ASD? Do factors such as the level of dependency and the child's age relate to the level of need in families of children with ASD? In order to address these questions, the primary aim of this research is to identify the needs of families of children with ASD, examining the relationship between the identified needs and both the level of dependency and the age of the individual.

To address this issue, the present study adopts a mixed-methods approach. The qualitative component of the research allows for an in-depth exploration of the needs, concerns, and experiences of families with children diagnosed with Autism Spectrum Disorder (ASD), aiming to provide a more comprehensive understanding that complements the quantitative findings. This mixed approach is particularly useful for understanding emotional and social dimensions that quantitative methods alone cannot fully capture. Through qualitative analysis, it is possible to capture the emotions and perceptions of families, facilitating the identification of key factors that could improve support programs and interventions, a perspective often overlooked in purely quantitative studies.

Although there is existing research addressing the needs of families with children with ASD, few studies have made direct comparisons between these needs and those of families with neurotypical children or children with other disabilities. This gap limits the ability to identify significant differences that could inform broader support policies and practices. The present study contributes to filling this gap by focusing exclusively on the needs of families with children with ASD.

While some quantitative studies measure the needs of these families, few adopt a qualitative approach to explore the personal experiences and perceptions of parents. This work aims to fill that gap through interviews and qualitative analysis, providing a richer and more nuanced understanding of the daily realities faced by these families. We also highlight how the findings could contribute to the design of more effective interventions that are better adapted to the real needs of these families.

2. Methods

2.1. Design of the research project

The present study employed a non-experimental ex post facto methodology, with the aim of providing a precise response to the main research objective: to assess the current situation and circumstances of families with members diagnosed with Autism Spectrum Disorder, focusing particularly on those with school-aged individuals with ASD. The selected methodological approach allowed for the examination of existing conditions without manipulating variables. Additionally, a mixed-method design was adopted, integrating both correlational and descriptive analyses. The descriptive analyses aimed to identify the specific needs of families, including those of students with ASD, while the correlational analyses examined the relationships between various factors affecting these needs. This comprehensive methodology facilitated a deeper understanding of the complexities faced by families and their school-aged children with ASD, contributing to the development of targeted interventions.

2.2. Participants

The population of the present research consisted of families with school-aged children with ASD residing in the Community of Madrid (Spain). The study employed a purposive non-probabilistic sampling method, with a non-random selection of participants based on ease of access. The selected families shared a key common characteristic: the presence of a family member with ASD.

The sample comprised a total of 33 families. Among those who completed the questionnaire, the majority were mothers (28), followed by fathers (4), and one sibling (1) of the individual with ASD.

Table 1 shows the general characteristics of the family member with ASD.

2.3. Instrument

The information was collected using the Family Needs Survey developed by Bailey and Simeonsson (1988), which was subsequently revised by the authors themselves (Bailey & Simeonsson, 1990). Since this scale was originally designed to assess the needs of families with members having disabilities of various etiologies, for the purposes of the present research, the scale was translated into Spanish, adapting the terminology to the context of families with members diagnosed with ASD.

The administered instrument was organized into several sections, including additional items to gather the information under study. The first section contained sociodemographic questions that allowed for the collection of relevant information from the surveyed sample; the second section consisted of the Family Needs Survey by Bailey and Simeonsson (1988, 1990), while the third and final section included additional qualitative questions enabling respondents to provide deeper insights into the phenomenon being studied.

It is important to specify that the aim of the second section was to analyze the degree and types of needs of the surveyed families through the 35 items that make up the Bailey and Simeonsson (1988) and Bailey and Simeonsson (1990). These items are organized into seven distinct dimensions (see Table 2) and offer three possible response categories: 1 “I do not need help,” 2 “I am not sure,” and 3 “I need help.”

Table 2 shows the general structure of the tool.

Since each dimension has a different number of items, the analysis was conducted by calculating the average for each dimension, which will allow for more accurate comparisons. Therefore, each dimension will have a score ranging from 1 to 3, corresponding to the available response options.

Regarding the third dimension of the instrument, it is notable that a set of questions aimed to collect qualitative information, allowing families the opportunity to express their most important needs based on their personal circumstances. Family members were also asked to categorize the expressed needs according to the type of support required (emotional, informational, logistical, and/or financial).

The survey was administered both in paper format and through the web application “Google Forms,” depending on the case, to facilitate access and participation of the sample in the research.

Table 1
Description of family member with ASD.

N° of persons with ASD		33
Gender	Male	26
	Female	7
Degree of dependence	No dependence	11
	Level 1	8
	Level 2	6
	Level 3	8
Age interval	0–6 years	16
	6 to 12 years	12
	12 to 19 years	5

Table 2
Dimensions of Family Needs.

Dimensions	Interval	N.° Items
Information	1–7	7
Family and social support	8–15	8
Financial	16–21	6
Explaining to others	22–26	5
Care of family member with ASD	27–29	3
Professional support	30–32	3
Community services	33–35	3
Total		35

2.4. Data analysis

For the present study, both descriptive and correlational analyses were conducted. In the case of the descriptive analyses, means, standard deviations, and coefficients of variation were calculated. The correlational analyses began with the Kolmogorov-Smirnov test to assess the normality of the sample distribution. The results indicated that, for the relationship between family needs and the degree of dependence, the normality assumption was not met ($p < 0.05$), so the Spearman correlation test was applied. In contrast, for the analysis of the relationship between family needs and the age of individuals with ASD, the results confirmed that the sample met the normality assumption, and therefore the Pearson correlation test was used.

IBM SPSS® Statistics software, version 22, was used for the statistical analysis of the data, while the tool Atlas.ti was employed for the categorization and subsequent analysis of the qualitative data from the research.

The present study, registered under the number 41/2022, has received ethical approval from the Ethics Committee of the Universidad Francisco de Vitoria, ensuring compliance with the applicable ethical and legal principles for research involving human participants.

3. Results

3.1. Family needs associated with ASD

The analysis of the research results begins by considering the main objective of the study, examining the statistical data regarding the needs of families across the various evaluated dimensions.

Table 3 provides a breakdown of each of the dimensions, indicating the indices of need for each. As the table shows, the need for Information is the most salient, scoring 2.6 from a minimum of 1 to a maximum of 3. It should be noted that the scores for this dimension are very homogenous (CV = 18.8 %) and are also the highest, with a significant representation in the final average needs score.

Table 3
Descriptive analysis of family needs.

Dimensions	Min	Max	Mean	Standard Deviation	CV*
Information	1	3	2.6	0.49	18.8 %
Family and social support	1	3	1.9	0.60	31.5 %
Financial	1	3	1.8	0.64	35.5 %
Explaining to others	1	3	1.9	0.63	33.1 %
Care of family member with ASD	1	3	2.0	0.66	33.0 %
Professional support	1	3	1.8	0.66	36.6 %
Community services	1	3	2.3	0.65	28.2 %

* *CV = Coefficient of variation.*

The need for professional support and financial expressed by families received the lowest score among all dimensions of the study, with a mean of 1.8. This suggests that, in general, families do not perceive professional support and financial as a high priority compared to other dimensions, such as care of family or community services. The homogeneity in the scores indicates that, although there are variations in the perception of the need for professional support (CV = 36.6 %) and financial (CV = 35.5 %), these are moderate, suggesting a general trend toward a lower urgency in this area.

3.2. Family needs in relation to degree of dependence

Table 4 below shows the scores obtained for family needs for each of the dimensions according to different degrees of dependence (no dependence, level 1, level 2 and level 3).

Table 4
Statistical data on the needs of families according to degree of dependence.

Dimensions	Degree of dependence	Min	Max	Mean	SD*	CV*
Information	No dependence	1	3	2.5	0.62	24.8 %
	Level 1	1.7	3	2.6	0.53	20.3 %
	Level 2	2.1	3	2.5	0.36	14.4 %
	Level 3	2	3	2.6	0.42	16.1 %
Family and social support	No dependence	1	3	2.0	0.54	27.0 %
	Level 1	1	3	2.1	0.64	30.4 %
	Level 2	1.2	2	1.5	0.33	22.0 %
	Level 3	2	3	1.8	0.72	40.0 %
Financial support	No dependence	1	3	1.8	0.73	40.5 %
	Level 1	1	3	1.7	0.67	39.4 %
	Level 2	1.1	2.3	1.7	0.49	28.8 %
	Level 3	1	3	2.0	0.72	36.0 %
Explaining to others	No dependence	1	3	1.8	0.58	32.2 %
	Level 1	1.8	3	2.3	0.43	18.6 %
	Level 2	1	3	1.6	0.70	43.7 %
	Level 3	1	3	1.9	0.78	41.0 %
Care of family member with ASD	No dependence	1	3	1.9	0.82	43.1 %
	Level 1	1.3	2.6	2.1	0.43	20.4 %
	Level 2	1	2.6	1.8	0.58	32.2 %
	Level 3	1	3	2.1	0.61	29.0 %
Professional support	No dependence	1	3	1.9	0.70	36.8 %
	Level 1	1	2.3	1.7	0.66	38.8 %
	Level 2	1	2.3	1.5	0.62	41.3 %
	Level 3	1	3	1.8	0.71	39.4 %
Community services	No dependence	1	3	2.5	0.68	27.2 %
	Level 1	1	3	2.3	0.80	34.7 %
	Level 2	2	3	2.3	0.73	31.7 %
	Level 3	1.6	3	2.2	0.42	19.0 %

* CV = Coefficient of variation, SD=Standard deviation.

The analysis of family needs in relation to the level of dependency shows numerically similar scores across different levels of dependency. However, the results of the Spearman correlation test (Table 5) indicate that there is no statistically significant relationship between these variables, suggesting that family needs are not directly dependent on the degree of dependency of the individual with ASD.

In this regard, it is noteworthy that the dimensions with the highest average scores were the information and community services dimensions, with both obtaining scores above 2 points out of 3. On the other hand, the lowest average scores were found in the financial and professional support dimensions, with scores below 2 points out of 3.

Considering the levels of dependency, it can be highlighted that, in general, individuals with level 1 dependency tend to present the highest scores in most dimensions. However, in some specific dimensions, such as the explanation to others, families of individuals without dependency reported higher scores.

Finally, in the case of families where the degree of dependency of the individual with Autism Spectrum Disorder is not administratively recognized, the scores, in most cases, are similar to those seen in families with a child at level 1 of dependency, except in the dimension of explanation to others, where a lower score was observed.

Table 5 below shows the results of the Spearman's correlation test of the index of needs of families of children with ASD and the degree of dependence. The results of the Spearman correlation test confirm the absence of statistically significant relationships between the degree of dependency and family needs ($p > 0.05$). Specifically, all correlation coefficients are low, ranging from −0.033 for the information dimension to −0.268 for community services, with all significance levels exceeding 0.05. This suggests that, regardless of the level of dependency, families face similar challenges in meeting their needs. Consequently, interventions should be designed considering a broad range of support strategies that address these common challenges rather than assuming that higher dependency levels automatically translate into greater family needs.

3.3. Family needs in relation to age of the person with ASD

The following presents the results of the questionnaire regarding family needs, segmented according to the age of the individual diagnosed with Autism Spectrum Disorder (ASD). To facilitate the analysis and presentation of the results, ages have been grouped into three intervals: from 0 to 6 years, from 6 to 12 years, and from 12 to 19 years. This categorization enabled a better understanding of the variations in family needs based on the development and circumstances of children and adolescents with ASD.

Table 6 shows the specific results for each of the dimensions.

The results related to family needs indicate that the age range of 0 to 6 years presents the lowest average score, with the financial dimension being identified as the area where the least support is needed, showing a mean score of 1.6 out of 3 (CV = 45 %). In contrast, the information dimension reports the highest score, with a mean of 2.5 out of 3 (CV = 22.8 %).

Table 5
Spearman's correlation between needs and degree of dependence.

Dimensions	Correlation coefficient	Sig. (bilateral)
Information	−0.033	0.857
Family and social support	−0.216	0.228
Financial	0.067	0.713
Explaining to others	−0.024	0.896
Care of family member with ASD	0.060	0.741
Professional support	−0.110	0.542
Community services	−0.268	0.132
TOTAL NEEDS	−0.095	0.597

Table 6
Statistical data on the needs of families according to the age of the person with ASD.

Dimensions	Age	Min	Max	Mean	SD*	CV*
Information	0 to 6	1	3	2.5	0.57	22.8 %
	6 to 12	1.71	3	2.6	0.47	18.0 %
	12 to 19	2.4	3	2.6	0.31	11.9 %
Family and social support	0 to 6	1	3	1.8	0.62	33.4 %
	6 to 12	1	3	1.8	0.63	35.0 %
	12 to 19	1.2	2.5	2	0.53	26.5 %
Financial	0 to 6	1	3	1.6	0.72	45.0 %
	6 to 12	1	3	2	0.58	29.0 %
	12 to 19	1.3	2.6	2	0.54	27.0 %
Explaining to others	0 to 6	1	2.6	1.7	0.56	32.9 %
	6 to 12	1	3	2.1	0.62	29.5 %
	12 to 19	1	3	2.3	0.79	34.3 %
Care of family member with ASD	0 to 6	1	3	1.9	0.73	38.4 %
	6 to 12	1	2.6	2.1	0.51	24.2 %
	12 to 19	1	2.6	2.1	0.64	30.4 %
Professional support	0 to 6	1	3	1.8	0.74	41.1 %
	6 to 12	1	2.3	1.7	0.56	32.9 %
	12 to 19	1	2.3	1.8	0.73	40.5 %
Community services	0 to 6	1	3	2.4	0.73	30.4 %
	6 to 12	1.3	3	2.3	0.47	20.4 %
	12 to 19	1	3	2.4	0.86	35.8 %

In contrast, the age group of 12 to 19 years exhibits the highest average score, with the highest mean recorded in the information dimension (M = 2.6; CV = 11.9 %), as opposed to the professional support dimension, which shows the lowest mean (M = 1.8; CV = 40.5 %). Based on these findings, the results obtained from the Pearson correlation test will be analyzed, applied to both the total family needs scores and each specific dimension.

As shown in Table 7, in general terms, no significant relationship is observed between the total family needs score and the age of the individual with Autism Spectrum Disorder (ASD) ($p = 0.304$), suggesting that family needs are not correlated with the age of the diagnosed member. However, when examining individual dimensions, a statistically significant relationship is highlighted in the dimension of "explaining to others," with a moderate correlation coefficient ($r = 0.367$; $p < 0.05$). This implies that as the age of the individual with ASD increases, so do the family needs related to the ability to communicate and explain their situation to others.

Table 7
Pearson's correlation between family needs and age of the person with ASD.

Dimensions	Pearson's correlation	Sig. (bilateral)
Information	0.090	0.620
Family and social support	0.053	0.769
Financial	0.247	0.165
Explaining to others	0.367*	0.035
Care of family member with ASD	0.147	0.413
Professional support	−0.085	0.639
Community services	0.000	1.000
TOTAL NEEDS	1.000	0.304

3.4. Vision of family needs according to age and degree of dependence

To conclude the analysis of the results obtained from the tool used, it can be stated that the scores related to family needs exhibit slight non-significant variations based on the age and level of dependence (No dependence, Level 1, Level 2, and Level 3 of dependence) of individuals with Autism Spectrum Disorder (ASD). In particular, Fig. 1 shows that the age range of 12 to 19 years corresponds to the highest scores, with Level 1 dependence recording the highest mean (M = 2.5), while Level 2 reflects the lowest scores (M = 1.7) regarding family needs.

In summary, the average scores are above 1.5 out of 3, indicating a medium to high level of needs. However, no clear trend is identified concerning age or degree of dependence, as the results appear relatively homogeneous across the different groups analyzed.

3.5. Priority needs of families and types of support

In this section, we analyze the third and final part of the instrument. As previously noted, this section is dedicated to examining the qualitative information expressed by families regarding their most urgent needs ranked by order of importance, as well as the types of support they require. To facilitate data analysis, responses were quantified and grouped, employing a scoring system that assigned a value of 5 to the most valued need and a score of 1 to the fifth, thereby establishing a priority ranking for each identified need. The families' responses concerning expressed needs were categorized into five distinct areas: familial (needs related to dynamics and support within the family unit), educational (needs associated with training and educational support), social (needs related to connections and interactions with the community or social environment), financial (economic needs or those concerning monetary resources) and healthcare (needs concerning medical treatment and overall well-being).

Based on the establishment of these categorical areas and dimensions, the information expressed by families was analyzed, allowing for the identification of their specific needs in various domains. In the familial category, families highlighted the need for support in caring for children or individuals with Autism Spectrum Disorder (ASD). They also emphasized the importance of having sufficient socio-familial leisure time, which they considered essential for strengthening family dynamics. Within the educational category, families expressed concerns related to support during childhood and adolescence. These included behavioral management, fostering autonomy, identifying appropriate schooling, accessing adequately trained professionals, and improving the overall quality of education provided. In the social category, the identified needs focused on ensuring social opportunities for children with ASD and promoting greater public awareness and understanding of the disorder. Families regarded these aspects as crucial for enhancing social integration. The financial category reflected the economic challenges families faced in covering the costs associated with therapies, housing, transportation, and other essential services required by individuals with ASD. Finally, the healthcare category underscored the need for access to specialized therapies provided by professionals familiar with ASD, such as teachers, psychologists, psychiatrists, and dentists. Thus, the needs expressed by families were organized into these categories, offering a clear framework for understanding their priorities and areas where support is most urgently required.

It is important to highlight that the analysis of this section reveals that families express the greatest need within the educational category, with a significantly elevated score ($N = 183$) compared to other areas. Conversely, financial support occupies the lowest priority (N = 18), indicating a considerable gap in this aspect. Within the educational

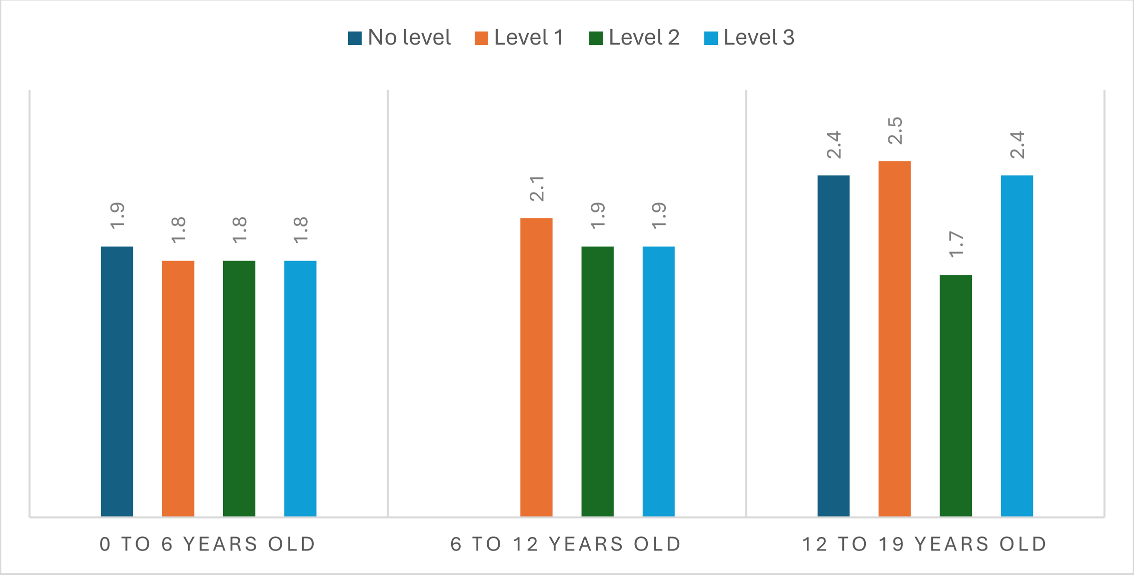

Fig. 1. Needs average grouped by age and dependency level.

domain, families particularly emphasize the need for access to information, which scores much higher than other concerns (fi = 34). In contrast, financial assistance receives the lowest scores (fi = 16). Overall, these findings underscore that families of children with ASD prioritize educational needs, especially concerning access to information, significantly above needs related to familial support, social interaction, healthcare, and financial assistance.

4. Discussion

The results obtained and analyzed confirm that the present study has achieved its primary objective by identifying the main needs of families with children diagnosed with Autism Spectrum Disorder (ASD). Additionally, it has also established the potential relationship between the degree of dependency and the age of the individual with ASD. The following outlines the scope of the results obtained in relation to the objectives set forth in the study.

The research has detailed the current situation of families with a school-aged member diagnosed with ASD concerning their needs across several dimensions: information, family and social support, financial support, the capacity to explain the condition to others, healthcare, professional support, and community services. The results provide an overview of the families' needs, both globally and within each specific dimension.

The analysis of the results reveals that families of children with Autism Spectrum Disorder report scores above 1.5 out of 3 in all evaluated dimensions, indicating a widespread perception of need across all analyzed areas. This trend is observed in the descriptive results presented in the analysis section (Table 3), where mean values above this threshold are reported in all studied categories of need. This finding aligns with those of Cañete et al. (2018) and Weissheimer et al. (2021), who identified considerable needs expressed by these families in specific areas such as access to accurate information and the ability to share experiences with others. Similarly, the findings align with similar studies that confirm the impact of ASD on families concerning needs related to therapeutic services and professional support (Abadia & Torres-Lista, 2019; Dieleman et al., 2018a, 2018b).

Although this study has determined the relationship between families' needs and the degree of dependency, the results of the Spearman correlation test indicated that there is no statistically significant relationship between the degree of dependency (No dependence, Level 1, Level 2, and Level 3 of dependence) and the family needs index. This finding contrasts with the results of Rogge and Janssen (2019), who found that higher degrees of dependency require greater needs in terms of financial assistance and educational and healthcare services. The homogeneity in results across different levels of dependency suggests that the needs arising from ASD have particular characteristics that vary according to the degree of dependency, which can be attributed to the wide-ranging associated symptomatology (Hodgetts et al., 2015). Although uniformity in scores was observed, Level 1 demonstrated higher results, which could indicate that greater autonomy and awareness of the individual with ASD translate into higher psychological, emotional, or social needs, evidenced in dimensions such as the need for information and social support (Kapp, 2018).

Regarding the relationship between family needs and the age of the individual with ASD, it was observed that families with children aged 12 to 19 years exhibited the highest levels of need. However, the Pearson correlation test did not show significant relationships, suggesting that the assumption that younger age corresponds to greater needs does not hold. This finding is consistent with research conducted by Eaves and Ho (2008) and Rogge and Janssen (2019), which revealed that the needs expressed by families and individuals with ASD tend to increase progressively with the age of the diagnosed individual, especially among those requiring a higher level of support.

Despite the scarcity of studies comparing family needs by age groups, it is noteworthy that the highest scores in the 12 to 19 age range may be linked to emotional and social factors inherent to adolescence, where social interaction takes on greater importance (Orben et al., 2020). Additionally, the relationship between the degree of dependency and age suggests that the elevated needs in this range may result from greater cognitive ability and autonomy, intensifying awareness of their own difficulties, which is exacerbated by the typical emotional instability of adolescence. In summary, the needs associated with ASD are broad and may vary according to the degree of dependency and age (Jensen & Spannagel, 2011).

Finally, after the qualitative analysis, it has been identified that families perceive significant needs in the areas of educational support and access to information. The last section of the tool allowed respondents to specify their families' needs, highlighting the importance of education in the lives of these families. This result emphasizes the necessity for educators and education professionals to be aware of families' demands, providing them with adequate resources and support throughout the educational and intervention processes (Flannery & Wisner-Carlson, 2020; Syriopoulou-Delli et al., 2016). It is significant that educational support and information are fundamental for families of children with ASD, which aligns with the conclusions of Henao and Amariles (2021), who identified that families' greatest need is to obtain accurate information to make informed decisions regarding educational interventions that facilitate their children's development. The findings of Bejarano-Martín et al. (2020) also reflect that a substantial percentage of families feel disoriented following the initial diagnosis due to a lack of information about their children's needs. This reiterates that information is the most demanded type of assistance by families. Finally, the results are consistent with those of Cañete et al. (2018), who emphasized the importance of support from competent professionals who adequately address the needs of children in the educational domain.

The findings of this study not only provide an in-depth understanding of the needs of families with children diagnosed with Autism Spectrum Disorder (ASD), but also have significant practical implications that can contribute to the design and improvement of policies and support programs for both families and educators in inclusive educational settings.

Firstly, the results reveal key areas where intervention can provide more effective support to these families. Specifically, the identification of emotional, educational, and social needs, among others, provides a solid foundation for developing interventions that are better aligned with the everyday realities faced by families (Solomon & Chung, 2012). These interventions could be fundamental in improving the experiences of families with children with ASD in the educational environment, and, in turn, facilitate the effective inclusion of children with this condition in classrooms (Alves et al., 2023).

In this context, it is crucial to highlight how the findings of this study can be used to design programs tailored to the real needs of families, promoting more personalized and targeted support. This approach would not only assist families in their parenting responsibilities (Pepperell et al., 2018) but also provide educators with the necessary tools to better understand family dynamics and offer more appropriate support to children with ASD in educational settings (Vassallo et al., 2020). In this way, it contributes to creating an inclusive environment that takes into account not only the needs of children with ASD but also those of their families, generating a positive impact on both groups (Goldrich et al., 2018).

Additionally, a significant gap has been identified in the existing literature regarding the understanding of family needs within the framework of inclusive education. While some studies have addressed the needs of families with children with ASD (Dieleman et al., 2018a, 2018b; Kiami & Goodgold, 2017; Papoudi et al., 2021; Seymour et al., 2022; Shorey et al., 2020), few have explored this issue in the context of inclusive education and in comparison to the needs of other families with children with disabilities or neurotypical children (Brydges & Mkandawire, 2020; Imaniah & Fitria, 2018). This gap in research limits our ability to identify key differences that could be useful for informing inclusive educational policies and practices. This study contributes to filling this gap by focusing exclusively on the family needs of children with ASD and underscores the importance of addressing these needs from a comprehensive perspective that considers both the well-being of the children and that of their families.

Therefore, this work not only expands the understanding of the specific needs of families with children with ASD, but also provides a foundation for future research that seeks to explore more broadly the implications of these needs in inclusive education. The importance of studying family needs in this context is crucial, as it can generate valuable recommendations for the implementation of more effective inclusive educational strategies, based on a deeper and more nuanced understanding of the realities faced by both families and children with ASD in their educational process.

This study presents several limitations that must be considered when interpreting the results. Firstly, the sample used is relatively small, which limits the generalizability of the findings. A study with a larger sample could provide more robust and representative results, improving the relevance and generalizability of the findings. Additionally, the analysis focused exclusively on families with children diagnosed with Autism Spectrum Disorder (ASD), without including families with children with other disabilities or without disabilities. This limitation prevents conducting comparative analyses between different groups, which could offer a broader understanding of the support needs and the conditioning factors affecting family systems.

It is suggested that future research broaden the focus to include families with children without disabilities and those with other disorders, in order to identify potential differences and similarities that could enrich the understanding of family needs in various contexts. Furthermore, the gender of caregivers is another important factor to consider, as the majority of the participants in this study were mothers, which could introduce bias in the interpretation of the results. It would be valuable to address the impact of caregiver gender in future studies, incorporating a more balanced representation of fathers and mothers.

Another limitation is that a portion of the sample's dependency level of the child with ASD was unknown, either because the family did not provide this information or chose not to disclose it.

In terms of future directions, it is proposed that further research explores additional aspects related to families of children with ASD, such as quality of life, difficulties in accessing appropriate information, and educational challenges. Moreover, it is recommended to conduct a regression analysis to identify potential predictors of the needs experienced by these families. This approach would allow the exploration of how variables such as the child's age, level of dependence, and other sociodemographic and contextual factors might contribute to explaining variations in these needs. Such an analysis could provide a more detailed understanding of the interaction between these factors and guide the development of more specific and effective support interventions for families of children with ASD.

5. Conclusion

In general, it can be concluded that families with members diagnosed with Autism Spectrum Disorder have needs that score above average in all the dimensions analyzed. This underscores the urgent need to improve the support provided to these families. It is essential that assistance is adequate across all areas, from effective healthcare and appropriate information from the initial diagnosis to education and social services that help families face the challenges associated with the disorder. The primary objective should always be to alleviate the burden on these families as much as possible, allowing them to progress while feeling supported and understood by their immediate environment and society, thus moving toward a socially inclusive reality.

CRediT authorship contribution statement

Laura Serrano Fernández: Writing – review & editing, Writing – original draft, Supervision, Investigation, Conceptualization. **Daniela Henao Campo:** Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Esther Vela Llauradó:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Conceptualization. **Laura Martín Martínez:** Writing – review & editing, Writing – original draft, Validation, Supervision, Investigation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

References

Abadia, P., & Torres-Lista, V. (2019). Impacto psicosocial del diagnóstico del Trastorno del Espectro Autista (TEA) en los principales cuidadores. *Investigación y Pensamiento Crítico, 7*(1), 27–39.

Alves, L., de Marilak, L., de Souza, D., de Alcântara, J. P., Alfonso, E., Furtado, R., … L., & Dias, L. M. N.. (2023). The importance of integrating pedagogical strategies and family support for the school inclusion of autistic students: A systematic review. *Journal of Business and Management, 25*(12). https://doi.org/10.9790/487X-2512030917

Anchesi, S. D., Corallo, F., Di Cara, M., Quartarone, A., Catalioto, R., Cucinotta, F., & Cardile, D. (2023). Autism and ADHD: A literature review regarding their impacts on parental divorce. *Children, 10*(3), 438. https://doi.org/10.3390/children10030438

Asociación Americana de Psiquiatría. (2013). *Guía de consulta de los criterios diagnósticos del DSM-5™*. American Psychiatric Publishing.

Bailey, D., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *The. Journal of Special Education, 22*(1). https://doi.org/10.1177/002246698802200113

Bailey, D., & Simeonsson, R. J. (1990). *Family needs survey (revised)*. FPG Child development institute: The University of North Carolina at Chapel Hill.

Befi, M., Bemmel, V., Samelson, D., Sneed, L., & Hoobing, J. (2023). Parents' experience of the diagnosis of autism spectrum disorder: Opportunities for marriage and family therapists. *The Family Journal, 31*(3), 346–356. https://doi.org/10.1177/10664807231157 02

Bejarano-Martín, Á., Canal-Bedia, R., Magán-Maganto, M., Fernández-Álvarez, C., Cilleros-Martín, M. V., Sánchez-Gómez, M. C., … Posada de la Paz, M. (2020). Early detection, diagnosis and intervention services for young children with autism spectrum disorder in the European Union (ASDEU): Family and professional perspectives. *Journal of Autism and Developmental Disorders, 50*, 3380–3394. https://doi.org/10.1007/s10803-019-04253-0

Brydges, C., & Mkandawire, P. (2020). Perceptions and experiences of inclusive education among parents of children with disabilities in Lagos. *Nigeria. International Journal of Inclusive Education, 24*(6), 645–659. https://doi.org/10.1080/13603116.2018.1480669

Cañete, M., Sánchez, M. C., & Corcho, P. (2018). Necesidades de apoyo percibidas por padres de niños con autismo entre 2-5 años, en México. *Siglo Cero, 49*(3), 75–93. https://doi.org/10.14201/scero20184937593

Chaidi, I., & Drigas, A. (2020). Parents' involvement in the education of their children with autism: Related research and its results. *International Journal of Emerging Technologies in Learning, 15*(14), 194–203. https://doi.org/10.3991/ijet.v15i14.12509

Chan, K. K. S., & Leung, D. C. K. (2020). The impact of child autistic symptoms on parental marital relationship: Parenting and coparenting processes as mediating mechanisms. *Autism Research, 13*(9), 1516–1526. https://doi.org/10.1002/aur.2297

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders, 48*, 3761–3772. https://doi.org/10.1007/s10803-018-3639-1

De la Torre, B., Martín, E., & Pérez, E. (2018). La valoración de las aulas TEA en la educación infantil: la voz de docentes y familias. *Siglo Cero, 49*(3), 55–73. https://doi.org/10.14201/scero20184935573

Dieleman, L. M., Moyson, T., De Pauw, S. S., Prinzie, P., & Soenens, B. (2018a). Parents' need-related experiences and behaviors when raising a child with autism spectrum disorder. *Journal of Pediatric Nursing, 42*, e26–e37. https://doi.org/10.1016/j.pedn.2018.06.005

Dieleman, L. M., Moyson, T., De Pauw, S. S., Prinzie, P., & Soenens, B. (2018b). Parents' need-related experiences and behaviors when raising a child with autism spectrum disorder. *Journal of Pediatric Nursing, 42*, e26–e37. https://doi.org/10.1016/j.pedn.2018.06.005

Dilleggi, E. S., Rosa, A. P., & Santos, P. L. (2019). Family functioning and environmental resources offered by families of children with mental disorders. *Salud Mental, 42*(5), 235–242. https://doi.org/10.17711/SM.0185-3325.2019.030

Downes, N., Lichtlé, J., Lamore, K., Orêve, M. J., & Cappe, E. (2021). Couples' experiences of parenting a child after an autism diagnosis: A qualitative study. *Journal of Autism and Developmental Disorders, 51*, 2697–2710. https://doi.org/10.1007/s10803-020-04744-5

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739–747. https://doi.org/10.1007/s10803-007-0441-x

Flannery, K. A., & Wisner-Carlson, R. (2020). Autism and education. *Child and Adolescent Psychiatric Clinics, 29*(2), 319–343. https://doi.org/10.1016/j.chc.2019.12.005

Goldrich, K., Summers, J. A., Chasson, G. S., & Mitchell, R. (2018). The association between family–teacher partnership satisfaction and outcomes of academic progress and quality of life for children/youth with autism. *Journal of Policy and Practice in Intellectual Disabilities, 15*(1), 16–25. https://doi.org/10.1111/jppi.12221

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Henao, L. I., & Amariles, W. A. (2021). Narrativas de transformación de dinámicas familiares asociadas a la presencia del diagnóstico de TEA en uno de sus miembros. *Horizontes Pedagógicos, 23*(1), 1–14. https://doi.org/10.33881/0123-8264.hop.23106

Hill, E. L., Jones, A. P., Lang, J., Yarker, J., & Patterson, A. (2015). Employment experiences of parents of children with ASD or ADHD: An exploratory study. *International Journal of Developmental Disabilities, 61*(3), 166–176. https://doi.org/10.1179/2047387714y.0000000037

Hodgetts, S., Zwaigenbaum, L., & Nicholas, D. (2015). Profile and predictors of service needs for families of children with autism spectrum disorders. *Autism, 19*(6), 673–683. https://doi.org/10.1177/1362361314543531

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities, 65*(1), 20–30. https://doi.org/10.1080/20473869.2017.1347228

Imaniah, I., & Fitria, N. (2018). Inclusive education for students with disability. *SHS Web of Conferences, 42*, 00039. https://doi.org/10.1051/shsconf/20184200039

Jensen, V. K., & Spannagel, S. C. (2011). The spectrum of autism spectrum disorder: A spectrum of needs, services, and challenges. *Journal of Contemporary Psychotherapy, 41*, 1–9. https://doi.org/10.1007/s10879-010-9161-1

Kamati, A., Shah, L. K., & BE, T. K.. (2021). Psychological burden among caregivers of children with autism Spectrum disorder at special schools. *MedS Alliance Journal of Medicine and Medical Sciences, 1*(2), 40–45. https://doi.org/10.3126/mjmms.v1i2.46495

Kapp, S. K. (2018). Social support, well-being, and quality of life among individuals on the autism spectrum. *Pediatrics, 141*(Supplement_4), S362–S368. https://doi.org/10.1542/peds.2016-4300N

Kiami, S. R., & Goodgold, S. (2017). Support needs and coping strategies as predictors of stress level among mothers of children with autism spectrum disorder. *Autism Research and Treatment, 2017*(1), 8685950. https://doi.org/10.1155/2017/8685950

Maciel, M. C., & Pereira, M. (2020). Autism: Impact of the diagnosis in the parents. *Jornal Brasileiro de Psiquiatria, 69*, 149–155. https://doi.org/10.1590/0047-2085000000276

Marriott, E., Stacey, J., Hewitt, O. M., & Verkuijl, N. E. (2022). Parenting an autistic child: Experiences of parents with significant autistic traits. *Journal of Autism and Developmental Disorders, 52*(7), 3182–3193. https://doi.org/10.1007/s10803-021-05182-7

Martinez, M., Thomas, K. C., Williams, C. S., Christian, R., Crais, E., Pretzel, R., & Hooper, S. R. (2018). Family experiences with the diagnosis of autism spectrum disorder: System barriers and facilitators of efficient diagnosis. *Journal of Autism and Developmental Disorders, 48*, 2368–2378. https://doi.org/10.1007/s10803-018-3493-1

Olsson, M. B., Westerlund, J., Lundström, S., Giacobini, M., Fernell, E., & Gillberg, C. (2015). "Recovery" from the diagnosis of autism–and then? *Neuropsychiatric Disease and Treatment, 999-1005*. https://doi.org/10.2147/NDT.S78707

Orben, A., Tomova, L., & Blakemore, S. J. (2020). The effects of social deprivation on adolescent development and mental health. *The Lancet Child & Adolescent Health, 4*(8), 634–640. https://doi.org/10.1016/S2352-4642(20)30186-3

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: A scoping review. *Review Journal of Autism and Developmental Disorders, 8*(2), 195–212. https://doi.org/10.1007/s40489-020-00210-1

Pepperell, T. A., Paynter, J., & Gilmore, L. (2018). Social support and coping strategies of parents raising a child with autism spectrum disorder. *Early Child Development and Care, 188*(10), 1392–1404. https://doi.org/10.1080/03004430.2016.1261338

Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders, 66*, Article 101415. https://doi.org/10.1016/j.rasd.2019.101415

Ráudez, L. G., Rizo, L. C., & Solís, F. J. (2017). Experiencia vivida en madres/padres cuidadores de niños/niñas con Trastorno del Espectro Autista. *Revista Científica de FAREM-Estelí, 21*, 40–49.

Rogge, N., & Janssen, J. (2019). The economic costs of autism Spectrum disorder: A literature review. *Journal of Autism and Developmental Disorders, 49*(7), 2873–2900. https://doi.org/10.1007/s10803-019-04014-z

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Cchild Psychology and Psychiatry, 17*(2), 229–245. https://doi.org/10.1177/1359104510365203

Seymour, M., Allen, S., Giallo, R., & Wood, C. E. (2022). 'Dads kind of get forgotten': The mental health support needs of fathers raising a child with autism Spectrum disorder. *Journal of Family Studies, 28*(4), 1199–1216. https://doi.org/10.1080/13229400.2020.1809491

Shorey, S., Ng, E. D., Haugan, G., & Law, E. (2020). The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-synthesis. *Autism, 24*(3), 591–604. https://doi.org/10.1177/1362361319886513

Smith, L. E., & Anderson, K. A. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education, 35*(2), 114–122. https://doi.org/10.1177/0741932513514 61

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*(2), 250–264. https://doi.org/10.1111/j.1545-5300.2012.01399.x

Syriopoulou-Delli, C. K., Cassimos, D. C., & Polychronopoulou, S. A. (2016). Collaboration between teachers and parents of children with ASD on issues of education. *Research in Developmental Disabilities, 55*, 330–345. https://doi.org/10.1016/j.ridd.2016.04.011

Valicenti-McDermott, M., Lawson, K., Hottinger, K., Seijo, R., Schechtman, M., Shulman, L., & Shinar, S. (2015). Parental stress in families of children with autism and other developmental disabilities. *Journal of Child Neurology, 30*(13), 1728–1735. https://doi.org/10.1177/0883073815579705

Vassallo, T., Dallos, R., & Stancer, R. (2020). Parent and teacher understandings of the needs of autistic children and the processes of communication between the home and school contexts. *Autism-open. Access, 10*(4). https://doi.org/10.35248/2165-7890.20.10.262

Villavicencio-Aguilar, C., Romero, M., Criollo, M., & Peñaloza, W. (2018). Discapacidad y familia: Desgaste emocional. *Revista de Investigación en Ciencias Sociales y Humanidades, 5*(1), 89–98. https://doi.org/10.30545/academo.2018.ene-jun.10

Weissheimer, G., Mazza, V. D. A., Freitas, C. A. S. L., & Silva, S. R. D. (2021). Informational support for families of children with autism Spectrum disorder. *Revista Gaúcha de Enfermagem, 42*, Article e20200076. https://doi.org/10.1590/1983-1447.2021.20200076