SOCIALIZATION GOALS AND ACTION STRATEGIES OF MOTHERS OF CHILDREN WITH SUSPECTED AUTISM SPECTRUM DISORDER

METAS DE SOCIALIZAÇÃO E ESTRATÉGIAS DE AÇÃO DE MÃES DE CRIANÇAS COM SUSPEITA DE TRANSTORNO DO ESPECTRO AUTISTA

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ABSTRACT: The main objective of the present research was to investigate the socialization goals and action strategies of mothers who have children with suspected Autism Spectrum Disorder (ASD). Twenty mothers of children with ASD aged from zero to six years, who receive care in a specialized center, participated in this study. For data collection, an interview about socialization goals and a socio-demographic questionnaire were used. For the treatment of the interview data, the Content Analysis technique was used. The results indicated that the category of self-improvement, which is related to autonomy and independence, was significantly the most desired goal of socialization. Regarding action strategies, the most used by the mothers was self-centeredness, which refers to the role of the parents as a model. In this way, the results contribute to the literature of this area and corroborates the importance of clarifying the developmental characteristics of the child with ASD for the parents and how they can act in favor of autonomy of the child. Taking into account the current unexplored view of society regarding ASD, this study aims to provide a rethinking of the strategies that make the child’s quality of life possible.


1 Introduction

Autism Spectrum Disorder (ASD) is characterized by persistent impairments in reciprocal social communication, social interaction and restricted and repetitive patterns of behavior, interests, or activities. These symptoms are applicable from early childhood and

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limit or impair the development of the child. The stage at which functional impairment becomes apparent will vary according to the characteristics of the individual and his/her environment. The disorder manifests itself in different ways depending on the severity of the autistic condition, the level of development and the chronological age (American Psychological Association [APA], 2014).

The discovery of the diagnosis of ASD can influence the way a family faces an adverse situation, which can lead its members to adapt immediately or in the long term. Thus, family resilience has a lasting result, and can have positive consequences in the development of the family group (Rooke & Pereira-Silva, 2012).

The care used by parents in raising their children is influenced by parental ethnotheories, which can be characterized as the organized set of ideas that are implicit in everyday activity, in the judgements, in the choices and decisions of caregivers, acting as role models for their parental practices, along with the physical and social environment, and also the shared, culturally and historically established customs and practices of care. The parental ethnotheories constitute the ‘Development Niche’, which contains three subsystems (Harkness & Super, 2005). The first subsystem is characterized by the physical and social environment; the second subsystem is the customs and care practices shared by history and the cultural site; and the third subsystem is the psychology of caregivers, also known as parental ethnotheories, better known as parental beliefs and expectations about their children.

In this way, it is understood that the three subsystems - physical and social environment, caregivers’ beliefs and care practices - have a connection, since one influences the other in a mutual way. In order to understand the strategies of action that parents use for the development of their children, it is essential to comprehend the beliefs, because they involve a set of ideas that are shared by the individuals of a cultural group (Harkness & Super, 2005).

Socialization goals, in turn, are described as the behaviors or states desired by parents and mothers for their children as they become adults. This definition may also include parents’ expectations about the knowledge and moral values their children should acquire throughout their lives. They are understood, therefore, as long-term goals estimated by the parents, who are influenced by the cultural context, interfering directly in the practices of parental care. More broadly, socialization goals are understood as a set of culturally constructed values and beliefs that are embodied in long-term goals that parents want for their children and that influence their care practices toward their children (Miller & Harwood, 2001).

Within the literature researched, three cultural models of parenting have been gaining strength to foster the impact of care practices on child development and socialization processes. The first - independent, individualistic or autonomous cultural orientation - refers to the construction of the self as unique and distinct, prioritizes personal goals and the needs of the individual in an autonomous and independent way. This type of model is characteristic of urban societies with a high level of schooling. The second model, denominated as interdependent, sociocentric or relational, comprises oneself linked to the other members of the family, thus prioritizing group goals and paying more attention to social roles, duties and obligations. This model is commonly found in rural environments based on subsistence economy (Keller, Borke, Yovsi, Lohaus, & Jensen, 2005). The third model - autonomous-
Socialization goals and Autism Spectrum Disorder

Relational - is understood as the junction of the characteristics of the first two models proposed by Heidi Keller. It encompasses autonomy and relationship, in which oneself is defined as autonomous, in relation to its action, and relational, due to its interpersonal closeness. This model is typical in middle-class families residing in the urban area and inserted in traditionally interdependent societies (Kagitcibasi, 2005).

Research was carried out at the Scientific Electronic Library Online (SciELO), at the Portal de Periódicos Eletrônicos de Psicologia (PePSIC) – Electronic Psychological Journals Database (PePSIC) and at the journal database of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (Capes) – Coordination for the Improvement of Higher Education Personnel – with the following keywords: socialization goals, parental values, parental expectations, parental beliefs, parenting, family and parents, combined with the word ‘autism’. Then, the term ‘autism’ was replaced with ‘autism spectrum disorder’ with the same combinations in the databases researched. This research was conducted between November 9th and 10th, 2017, using studies published within the last five years as the cut-off period. Regarding the theme of this study, it was verified that there are no studies in this sense; however, there are other studies that investigated the phenomenon in populations with atypical development in the Brazilian context. We highlight the studies on socialization goals and action strategies of parents and mothers of children with Down Syndrome (Portes, Vieira, & Faraco, 2016), and another study that discusses goals and socialization strategies that mothers of deaf children value for their children (Freitas & Magalhães, 2013).

The main objective of this study is to understand the goals of socialization and the strategies of action adopted by mothers of children with suspected Autism Spectrum Disorder. Based on this objective, the socio-demographic characteristics of the family and the target child were described. After that, the analysis of the socialization goals that mothers desired for their children when they became adults and the strategies they used for their children to reach their goals were analyzed.

2 Method

This research is characterized as exploratory and descriptive, with a qualitative approach. It is exploratory as a survey was carried out in the form of interviews with people who had practical experiences with the problem researched, with the objective of investigating and distinguishing concepts and ideas about the phenomenon. It is descriptive, because it had the objective of describing the characteristics of the population and of the studied phenomena (Gil, 2008).

2.1 Participants

In this research, twenty mothers of children aged up to six years with suspected Autism Spectrum Disorder or who were already diagnosed were interviewed. It is noteworthy that all the invited mothers accepted to participate in the research. The children were attended to by a multiprofessional team at the Specialized Rehabilitation Center (SRC II), located in southern Brazil. For the sample, mothers of children aged between 0 and 6 years diagnosed, according to DSM-5, with (299.00) Autism Spectrum Disorder or with this diagnostic
hypothesis during the evaluation process (APA, 2014) were included. The age group of the children was established as an inclusion criterion in the sample because it corresponds to one of the critical moments of human development, in which the parental investment is decisive for the survival of the children and for being representative of the possibilities of interaction described in the instrument to be used in this research.

2.2 INSTRUMENTS

A questionnaire that was developed by researchers linked to the Núcleo de Estudos e Pesquisa em Desenvolvimento Infantil (NEPEDI) - Center of Studies and Research in Child Development - at the Universidade Federal de Santa Catarina (UFSC) was used and adapted to the specificities of the population to be investigated in this study. It consists of twelve questions regarding family members’ data (number of members, age, sex), family income, parents’ schooling, working hours, presence of people who contribute to child care and issues related to child inclusion in school and specialized institutions. In addition, a semi-structured interview was carried out, developed by Harwood, Schoelmerich, Ventura-Cook, Schulze and Wilson (1996), and adapted to the Brazilian context in families of children with typical development by Seidl-de-Moura et al. (2008). This interview aims to identify long-term socialization goals and classify parental strategies for action. The questions selected were: 1. What qualities would you want your child to have as an adult?; 2. What do you think is necessary for him/her to develop these qualities?

2.3 DATA COLLECTION PROCEDURES

Initially, the invitation was made personally by the researchers while the mothers waited for the care of their child in the institution. If the mothers accepted, they were invited to go to a room provided by the institution, in which the researchers explained the objectives, the research methods and requested the signing of the Informed Consent Form. The interviews were conducted individually by the researchers in a reserved room. The application of all instruments took approximately 25 minutes and followed the validation criteria. For this, a voice recorder was used, and, later, the information was transcribed in full and the data analysis was carried out.

2.4 DATA ANALYSIS

The interviews were analyzed using the Content Analysis Technique (Bardin, 2011). All three steps of the analysis were followed, namely: a) pre-analysis; b) exploration of the material; and c) treatment of results, inference and interpretation. We worked with previous categories validated by the instrument, which were excluded. Thus, no description was classified in more than one category. The categories are:

- Self-improvement: concern for the child to become self-confident, independent and to fully develop his/her talents and abilities as an individual.
- Self-control: concern for the child to develop the ability to control negative impulses of greed, aggression or egocentricity.
- Emotion: concern for the child to develop the capacity for emotional intimacy with others, and to be loved.
- Social expectations: concern that the child meets the social expectations of being hardworking, honest and law-abiding.
- Good behavior: concern for the child to behave well, get on well with others and perform the expected roles well (good father, good mother, good wife, etc.), especially in relation to the family.

In addition to these categories, the classification of typical development created by Portes et al. (2016) was used. In this study on socialization goals of children with Down Syndrome (DS), due to the specificity of the population, the category called typical development (TD) was created as it refers to the concern that the child with DS can achieve a similar development with children without any disability despite their limitations. It was also observed to be an important factor for completion of the study.

The responses of the participants in each category were considered whenever their content expressed an approximation with the definition of the category. Therefore, the same participant’s response could relate to more than one category in her response to the questioning of their expectations about the development of her child as an adult.

The first question could still be classified in the individualist and sociocentric dimensions, as Harwood et al. (1996) pointed out, and adapted to the Brazilian context by Seidl-de-Moura et al. (2008):
- Individualist: construction of oneself as fundamentally unique and distinct; independence, autonomy, self-esteem, happiness, self-control to become a better person; self-improvement; self-overcoming. Qualities related to the categories self-improvement and self-control. To form this category, the frequencies of the two categories self-improvement and self-control were counted.
- Sociocentric: construction of oneself as fundamentally linked to other beings. It involves social interdependence, emphasis on respect, social network, belonging to a group or collectivity. Qualities related to categories: emotionality, social expectations and good behavior. In order to form this category, the frequencies of the three categories of emotionality, social expectations and good behavior were counted.

For the second question, the same author classifies in terms of possible strategies of action:
- Self-centered (SC): parents would act as role models or would provide role models, they would discipline, counsel, teach by demonstration or participation.
- Context-centered (CC): to provide good social opportunities; provide quality education, among others.
• Child-centered (ChC): when the child has an active participation in the process of developing certain qualities through the predisposition or autonomy to decide what to do and which way to go.

Then, the reliability test was carried out to evaluate whether the units of analysis were included in the appropriate categories. In order to perform this procedure, the researchers analyzed the interviews separately. The concordance index (CI) was above 70%, which was considered a reliable result to carry out the other statistical analyzes of this study. The frequencies of interview responses for each category were analyzed statistically, as well as the descriptive statistics (mean and standard deviation).

2.5 **Ethical aspects**

The project was approved by the Research Ethics Committee in August 2017 (Opinion no. 2,217,065). Legal-aged participants signed the Informed Consent Form.

3 **Results**

Initially, socio-demographic data will be presented in order to characterize the families of children with Autism Spectrum Disorder (ASD). Then, the results of the interview about the socialization goals and the strategies used by the mothers to reach expectations about the development of the children will be presented.

The mean age of the parents was approximately 32 years old (M = 32.90 SD = 7.94) and the mothers 35 years old (M = 35.75 SD = 8.34). It was observed in the family composition of the participants, in the majority of the families (n=19), that the child resides with the biological parents, that is, families of the nuclear type, except for only one family, in which the mother shares the care with the stepfather of the child. Regarding the marital status of these parents (n=18), the mothers declared themselves to be married or to be in a stable union. Regarding the number of people living in the house of the child, in the majority of families surveyed (n=13), the children with ASD have siblings, and in 7 (n=7) of the thirteen families, the siblings age is between seven and sixteen years old. In the families surveyed, there was a variation in the level of schooling of the parents, from unfinished Elementary School to unfinished Postgraduate studies. Nine mothers and fathers have graduated from High School, and 4 mothers and 5 parents have graduated from Higher Education.

With regard to the current activity of the father, it is important to emphasize that all perform some paid activity. Among them, 13 work a forty hour week, with the exception of only one who is currently unemployed. With regard to the mothers, 13 out of 20 do not have any paid work - they declared themselves to be housewives. Regarding family income, it was found that the income of the entire sample ranges from one to two and a half times the minimum wage.5

The age of the children studied varies from 26 to 66 months old, presenting (M= 42.5 SD = 11.22). Of all the children in the sample, a high prevalence of males was observed, with a

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5 Minimum wage equivalent to R$ 937.00 (approximately US$284.00), effective in 2017.
total of 15. With regard to schooling of the children, 16 attend regular school, and the others do not attend any type of educational institution. Regarding the age in months that the child entered the school, the mean was 23 months with a standard deviation of 17 (M = 23 SD = 17.01), which suggests a great variability in the period of admission of the child with ASD at school.

All children attend an institution with multidisciplinary care, and 10 of the 20 children do not have the diagnosis completed, as they are under evaluation by the SRC II service. Within this sample, only 5 were diagnosed with ASD at approximately 24 months of age.

Of the 16 children attending school, in 9 families the mother is the main person to take them to the institution and pick them up, and in 4 families, the mother and the father perform these tasks together or alternate them. Eighteen families do not have a caretaker or maid.

With regard to other caregivers who help raise children, in 14 families the mother stands out as the primary provider of basic care for her child, helping him/her feed and bathe. However, out of school, in relation to care, these mothers rely on their husbands for help (the target child’s father) and then on the grandmother. It is important to emphasize that in none of the families did the father remain solely responsible for the care of the child.

In the analysis performed on the first question for the interviewees, 220 responses were identified regarding the socialization goals. It was identified that all categories were mentioned by the participants. Table 1 below presents descriptive data regarding categories of socialization goals.

<table>
<thead>
<tr>
<th>Categories</th>
<th>f</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-improvement</td>
<td>107</td>
</tr>
<tr>
<td>Social expectancy</td>
<td>39</td>
</tr>
<tr>
<td>Good behavior</td>
<td>34</td>
</tr>
<tr>
<td>Emotionality</td>
<td>28</td>
</tr>
<tr>
<td>Typical development</td>
<td>11</td>
</tr>
<tr>
<td>Self control</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>220</strong></td>
</tr>
</tbody>
</table>

Table 1. Total coded responses of mothers, according to the categories of socialization goals

Source: Elaborated by the authors.
Legend: Sum of frequency of coded responses for each category.

Self-improvement (SI) categories, which refer to concerns that the child becomes self-confident, independent, and fully develops his/her talents and abilities as an individual, were the most desired with a total of 107 responses mentioned by the mothers during the interviews. One of the statements of the mothers who expressed this category was: ‘I want him to study, to have academic education’ (Mother 12).
Then, the category Social Expectation (SE) was the second most frequent in the statements of the mothers with 39 mentions, since this category refers to concerns that the child meets the social expectations of being hardworking, honest and law-abiding. This goal could be identified in the mothers’ statements, such as: ‘That he is a good person, be educated, a hard worker, mainly honest’ (Mother 4).

In the sequence, the category of Good Behavior (GB) stood out with a total of 34 times mentioned in the mothers’ statements, which is consistent with concerns that the child behaves well, gets on well with others and performs well in expected roles (good father, good mother, good wife, etc.), especially in relation to the family. In one of the interviews, the participant highlighted the category when reporting: ‘Becoming a man, a good man to be a good father, a good man to be a good son’ (Mother 4).

In the Emotivity category (E), classified by concerns that the child develops the capacity for emotional intimacy with others, and be loved, it was mentioned 28 times by the mothers. This can be exemplified through the statement of mother 14: ‘And also a quality that he sees the other and thus recognizes other people and sees and helps them’.

Regarding the Typical Development (TD), which refers to the concern that the child with ASD has a development similar to that of children without disabilities despite their limitations, was manifested by mothers eleven times. This goal can be identified in this statement: ‘That she is a normal teenager, […] that she has a normal future’ (Mother 18).

Finally, the Self-Control (SC1) category, related to concerns that the child develops the ability to control negative impulses of greed, aggression, or egocentricity, was mentioned only once. This single mention can be identified in the statement of mother 1: ‘For example, not to harm anyone, right’ (Mother 1). This result calls attention to the fact that, in the literature researched, children with ASD often present behavioral problems related to aggression. From the data, this research shows that mothers do not present this concern regarding the development of their children in the future.

Based on the responses mentioned by the interviewees, it was observed that most of these mothers outlined the socializing goals of their children involving social expectancy, emotionality and good behavior categories - which indicate the sociocentric model; and the self-improvement and self-control categories, which complete the individualistic model. We identified 209 responses related to these models, 108 being attributed to the individualist model and 101 to the sociocentric model.

It was observed that the mothers did not present significant differences regarding the individualist and sociocentric models. It was evident that the mothers value both goals related to the individualistic and the sociocentric dimensions. The individualist model refers to the construction of oneself as fundamentally unique and distinct; independence, autonomy, self-esteem, happiness, self-control to become a better person; self-improvement; self-overcoming. The sociocentric model refers to the construction of oneself as essentially associated with other beings, involving social interdependence, emphasis on respect, social network, belonging to group or colectivity.
Regarding the results obtained in relation to the mothers’ action strategies so that their children reach the desired goals for their development, the strategies most valued by the mothers was the Self-centered (SC), with a total of 63 responses. This strategy is associated with the parents, since they would act as a role model or would provide a role model to the children and would discipline, advise, teach the child by demonstration or participation. This strategy is evident in the statement of Mother 13, when she says: ‘That I give good examples to him, teach him how to get to people, how to talk, not to touch what is not his, all this I have already been teaching him’.

After that, the category with the highest frequency was Context-centered (CC), which is about offering good social opportunities, giving quality education, among others. It was mentioned 49 times by the mothers. This strategy was evident in the statement of Mother 9, when she reports: ‘With all of the multidisciplinary team I know that he will create these abilities’.

The Child-centered category (ChC), which refers to when the child has an active participation in the process of developing certain qualities by a predisposition or autonomy to decide what to do and which way to go, was referred to by the mothers 48 times. It can be exemplified in the statement of mother 2, when she reports: ‘She needs to learn to communicate’.

4 Discussion

Among the families surveyed, the differences between the roles played by the father and the mother in this context stand out. Generally, the mother is responsible exclusively for the care of the child, unlike the father who in all cases performs the task of financial provider and stays with the child only for a short time. The investigations of families of children with ASD have found similar results to the present study and reinforces the father’s more traditional role in guaranteeing resources and the mother’s in providing care (Meimes, Saldanha, & Bosa, 2015; Schmidt, Dell’Aglio, & Bosa, 2007; Smeha & Cezar, 2011).

With regard to socialization goals, the results obtained in this study show that mothers want their children with ASD to have values related to autonomy, independence, that they have a good job, they study, being those related to the category of self-improvement. However, this estimate on the development of children with ASD is directly linked to communication skills, but these qualities are often not consistent with the expected prognosis of an individual with ASD, since children are expected to have communication difficulties; thus interfering in social interaction as well as in the individual’s independence.

Because of the limited development of the child, parents often fear the future of their children. A central concern for them is whether the child will be able to live independently, especially when they are no longer present to provide care (Depape & Lindsay, 2015; Smeha & Cezar, 2011). On one hand, in Smeha and Cezar’s research (2011), some mothers realized that their child with ASD causes a discomfort in people because they look in a disapproving way, which denotes a gesture of prejudice. Mothers may interpret any discrimination directed at their children as if it was for them and, consequently, they feel fragile in social situations (Mannoni, 1999). On the other hand, the mothers participating in this study showed good expectations about the future of the child with ASD. This positive view of the child’s development can help
mothers cope with the adversities arising from raising their child with autism. It is understood that these qualities can be the result of the great advance of society in the understanding of the disability, mainly regarding ASD and its possibilities of treatment.

The goal of self-improvement was also found in other researches that used the same methodology used in this research, in families of children without disabilities (Bandeira, Seidl-de-Moura, & Vieira, 2009; Diniz & Salomão, 2010; Borges & Salomão, 2015; Lins, Salomão, Borges, Lins, & Carneiro, 2015); and with parents of children diagnosed with Down Syndrome (Portes et al., 2016); and in the study of children undergoing oncological treatment (Sant’Anna & Mendes, 2017).

According to Diniz and Salomão (2010), the concern with children when they reach adulthood to become self-sufficient, independent, that they have a good job, that they feel fulfilled, may be associated with a cultural issue that points to a tendency, even in Latin countries, to emphasize the principles of an individualistic society that values autonomy, independence and professional success. It was observed in the researched literature that this tendency comes from the decade of 1970, when parents began to prioritize development in relation to what their children will be in the future (Bandeira et al., 2009). In Sant’Anna and Mendes’s study (2017), the valorization of the goals related to the category of self-improvement, according to the authors, is associated with the health of the patients, that is, the mothers estimate that the children remain healthy, that they are healthy, that they are cured of the disease.

The second most estimated goal for mothers of children with ASD is associated with social expectations. Qualities like being honest, law-abiding, hardworking, are indispensable values for these mothers. This result can be related to Diniz and Salomão’s study (2010) carried out with parents of children with typical development, in which this goal was also the second most expected by the parents. They also contribute by pointing out that the emphasis for this category leads to the thinking of a culture that values disciplined behavior and adherence to norms, that is, sociocentric orientation that highlights the development of socially desirable qualities and that prioritizes the interpersonal relationship between child, family and society (Harwood et al., 1996). In addition, in Borges and Salomão’s research (2015), which investigated the goals of maternal socialization in the non-urban context, the category of social expectations was obtained as the second most esteemed goal by the mothers. The authors relate the choice for this category to a characteristic context of non-urban families, based on subsistence agriculture, in which families emphasize the autonomy of their children and prioritize the responsibilities related to society, in which they must meet the needs and obligations linked to these social groups.

The choice for goals related to social expectation may be tied to socio-demographic issues. In the research conducted by Lins et al. (2015), the authors emphasize that all the participants were religious, which suggests a valorization of goals oriented to intergroup relations and religions, such as respect for others, family and God.

In the study of mothers with deaf children, the goal of social expectation was the most desired. Thus, it is evident that this category is directly influenced by socio-demographic variables, since the value of the goals related to the social expectation category was higher in the group with less schooling, that is, mothers with a high level of education tend to give
more importance to the individualist goals than those with low level of education (Freitas & Magalhães, 2013).

On one hand, the mothers of children with ASD give similar importance to goals related to the individualistic cultural model as well as to the sociocentric model. On the other hand, the study of Portes et al. (2016), with the parents of children with Down Syndrome, also had the prevalence of the individualistic model, as well as in the study of Seidl-de-Moura et al. (2008), with mothers of children without disabilities from Rio de Janeiro, in which there is a predominance of the individualist model over the sociocentric.

Due to the balance in the frequency of individualistic and sociocentric parenting models, it can be said that mothers of children with ASD have a model of parenting with autonomous-relational orientation (Kagitcibasi, 2005). This model prioritizes that the children value the relation with other people and live in harmony with the group, without abandoning the autonomy and the independence. This model is evident in studies involving seven Brazilian capitals and the American countries, since the mothers wished for their children to be self-confident, independent, and professionally successful, at the same time they valued that they were honest and complied with their obligations towards the family and society (Bandeira et al., 2009; Diniz & Salomão, 2010; Vieira et al., 2010).

Another important aspect is related to the typical developmental category (TD), which involves the expectation of the mothers in relation to the desire that their children have a similar development to that of children without disabilities. The mothers of the children with ASD did not present this concern for the child. These results are different from the study of Portes et al. (2016) conducted with parents of children with Down Syndrome, in which the typical development category is the second most longed for by the parents. This difference between the studies can be explained by the fact that the children with Down Syndrome are marked by the physical characteristics that soon identify him/her as a person with a disability. This can make parents have to deal with the reality of having a child with a disability more directly from birth. However, children with ASD often do not present syndromic characteristics and, therefore, their disability is not very apparent, which may corroborate with parents who do not consider him/her as a person with a disability and so do not have a concern over the child presenting typical development in the future.

Finally, the Self-control category, which is related to concerns that the child develops the ability to control negative impulses of greed, aggression, or egocentricity, was mentioned only once in this study. This result calls attention to the fact that, in the literature researched, children with ASD often present behavioral problems, mainly related to aggressiveness (Gray, Keating, Taffe, & Brereton, 2012). The results of this research diverge from these investigations, because mothers do not present this concern regarding the future development of their children. Other studies with families of children with disabilities have also found results that approximate the findings of this research, such as Portes et al. (2016), who, in their research, obtained only two references related to this goal. In the study of Freitas and Magalhães (2013), the parents did not show expectation about the development of children with hearing impairment.

In order to achieve these goals, we sought to investigate the strategies used to achieve the goals estimated in the development of the participants’ children, as well as indicators of the
rearing practices. In this study, the most desired strategy refers to practices related to parents, that is, the self-centered strategy. It is possible for parents to believe that they are primarily responsible for helping the child reach their goals throughout their development, through the transmission of good examples, teaching, love, attention, and caring. In studies conducted with families of children with typical development, the researchers also identified the self-centered strategy as the most used (Bandeira et al., 2009; Diniz & Salomão, 2010). And with mothers of children with disabilities, the studies of Freitas and Magalhães (2013) and Portes et al. (2016) stand out. Therefore, studies with families of children with typical and atypical development seem to agree that, in order to reach expectations about the child’s development, the most used strategy is related to parental care.

Self-centered action strategies can be influenced by other variables. Diniz and Salomão (2010) point out that the age range of the children in their study varied from two to 40 months, during which time the child needs care to ensure their survival. Therefore, as the child grows, his/her developmental needs change and the parents’ beliefs about their own strategies and goals tend to change. In this way, it is understood that the age of the child is a direct influential factor in the strategies used by the parents, so as the child develops, and his/her social relations widen and the school phase begins, this strategy will possibly appear less and less (Diniz & Salomão, 2010). It is important to emphasize that the aforementioned study deals with children without disabilities, although the results are the same as in the present study. It should be emphasized, therefore, that the strategies adopted by the mothers may not be related to the child’s age range, but rather to their deficiency. Freitas and Magalhães’s study (2013) emphasizes that when the family receives the diagnosis of a child with a disability, conceptions about what it is to be a parent change. This crisis of identity and bonding is articulated with the beliefs and practices of parental care, directing the relationships established in the family group.

Context-centered and child-centered strategies presented similar results. With regard to the context-oriented strategy that involves factors such as giving social opportunities, which include education, health, among others, it is possible to highlight the importance of the social support network, which is characterized as a set of interpersonal relationships that the person considers meaningful. This can be made up of family, friends, coworkers or classmates, community people, and health professionals. Through this network, it is possible to receive social, emotional, cognitive and even financial support; it also favors human development and fulfills the needs of the person to relate to others. In addition, it provides comfort of belonging to a group, of being loved - important conditions for maintaining self-esteem (Brusamarello, Guimarães, Labronici, Mazza, & Maftum, 2011).

With the emergence of public policies and social support networks aimed at promoting the development and guaranteeing the rights of this population, allowing access to services, it is important to emphasize that this strategy can be associated with the service which all the families interviewed attend to, the Specialized Center for Rehabilitation (SCR II), where these children receive treatment. In addition, the social support networks provide information and guidance to families, as well as ordinances, resolutions and normative instructions that regulate the assistance, from the perspective of integral health care for the person with a disability, inaugurating an assistance model based on the multi-professional and
multi-disciplinary approach, with emphasis on actions to promote health, rehabilitation and social inclusion (Parâmetros Nacionais de Qualidade para Educação Infantil, 2006a, 2006b).

Finally, when comparing the frequency of all strategies, it is noted that the parents attribute less importance to the strategies focused on the child’s own abilities. However, this result is contradictory because mothers estimate goals related to the independence and autonomy of their children, and do not believe that their child can be a protagonist. In the study of Portes et al. (2016), this strategy was also the least used by the parents. Due to that, the authors add that even if the parents expect the child’s independence in adulthood, they do not seem to believe that the child with a disability can be the author of their development because they believe that, because of their condition, the child will be dependent on the help of the parents and their support network. This same result was found in the studies of Freitas and Magalhães (2013), involving deaf children, and Diniz and Salomão (2010), involving children with typical development, in which parents believe that they should be models for their children and instruct them, so that they can achieve the expected goals for their development.

5 Conclusion

The results of this research indicate that mothers expect their children to achieve autonomy and independence as they grow up. The main way to reach these goals are the strategies that they attribute to themselves as models for reaching these expectations. We concluded that the most desired goal is not consistent with the most used strategy. This may be related to a number of factors, including socioeconomic status, context, and broader culture in how mothers think about child rearing and how this may reflect their expectations about their future.

This study sought to fill a gap in the literature of this field through the presentation of some evidences found in this research, regarding what mothers of children with ASD want their children to have in the future. In this sense, the results obtained bring relevant contributions to the literature in the area and indicate the importance of clarifying the developmental characteristics of the child with ASD for the parents and how they can act in favor of the autonomy of the child so that he/she is also able to be the protagonist of his/her development trajectory. For further research, we indicate studies that enhance parents’ understanding of the future of their children.

References


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