

Schooling of people with Autism Spectrum Disorder (ASD) in adulthood: reports and perspectives of parents and caregivers of adults with ASD¹

Fernanda Duarte Rosa^a , Thelma Simões Matsukura^b , Carolina Elisabeth Squassoni^c 

^aCAPSij “Roda Viva”, Prefeitura Municipal de Campinas, Campinas, SP, Brasil.

^bDepartamento de Terapia Ocupacional, Universidade Federal de São Carlos – UFSCar, São Carlos, SP, Brasil.

^cPrefeitura Municipal de São Carlos, São Carlos, SP, Brasil.

Abstract: The Educational National Policy, within the perspective of inclusive education, orients teaching and learning systems to guarantee access since preschool until high school/vocational school. The literature on the field reviews the need for a greater understanding of schooling processes for people with ASD in the different stages of life. This study has aimed to identify the perspective of families of adults with ASD regarding the institutions that offer care to autistic people during adulthood. The study has also aimed to identify the educational trajectory, its positive aspects/challenges, under the outlook of their family members. The research methodology includes the provision of two questionnaires, subsequently analyzed under descriptive statistics and Collective Subject Discourse Methodology (CSD). In total, 67 parents/caregivers of adults with ASD, residents in 14 Brazilian states, were part of the study. The results reveal the exclusion experienced by these adults in their educational trajectories, since their childhood/adolescence, until their adulthood. Moreover, it is noted that most of them have been inserted only in special education institutions, with only eight reaching regular teaching institutions within adulthood. The reported challenges were related to inclusion, service quality and permanence in the educational institutions. As for positive aspects, the expansion of socialization and the gain of new skills have been highlighted. Ultimately, these family members showed their perspectives on characteristics institutions should have, in order to be considered suitable to care for people with ASD during adulthood, comprising individual and comprehensive care.

Keywords: *Autistic Disorder, Adult, Education, Family.*

Escolarização de pessoas com Transtornos do Espectro Autista (TEA) em idade adulta: relatos e perspectivas de pais e cuidadores de adultos com TEA

Resumo: A Política Nacional da Educação, dentro da perspectiva da educação inclusiva, orienta que os sistemas de ensino e aprendizagem garantam o acesso desde a educação infantil até o ensino superior/profissionalizante. A literatura da área revela a necessidade de uma maior compreensão acerca dos processos de escolarização para pessoas com TEA nas diversas etapas da vida. Este trabalho teve como objetivo identificar perspectivas de familiares de adultos com TEA em relação às instituições que se propõem a atenção aos autistas na vida adulta. Objetivou também identificar como foi o percurso escolar, os aspectos positivos e desafios, sob o ponto de vista de seus familiares. O método incluiu a administração de dois questionários, analisados através de estatística descritiva e da técnica do Discurso do Sujeito Coletivo (DSC). Participaram do estudo 67 pais/cuidadores de adultos com TEA residentes em 14 estados brasileiros. Os resultados evidenciam exclusão vivenciada por esses adultos em seu processo de escolarização desde o período da infância/adolescência até a idade adulta. Verifica-se que a maior parte destes autistas esteve inserida somente em instituições educacionais especiais, sendo que somente oito chegaram a instituições regulares de ensino

Corresponding author: Fernanda Duarte Rosa, CAPSij “Roda Viva”, Prefeitura Municipal de Campinas, Av. Brunoro de Gasperi, 280, Parque Prado, CEP 13044-165, Campinas, SP, Brasil, e-mail: fernandaduarterosa@yahoo.com.br

Received on Dec. 10, 2018; 1st Revision on Jan. 30, 2019; Accepted on Mar. 13, 2019.



na idade adulta. As dificuldades relatadas estavam relacionadas à inserção, qualidade dos serviços e permanência nas instituições escolares. Foram apresentados como pontos positivos a ampliação da socialização e o ganho de habilidades. Por fim estes familiares apresentam suas perspectivas sobre como deveriam ser as instituições aptas a receberem a pessoa com TEA, já em idade adulta, englobando atendimentos individualizados e de forma integral.

Palavras-chave: *Autismo, Adulto, Educação, Família.*

1 Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders, the DSM-Vos Autistic Spectrum Disorders (ASD) calls the Disorders as Autistic, Asperger's and Global Developmental Disorder Not Otherwise Specified, with variations being denominated according to the severity level. These disorders are characterized by the persistent deficits in social communication and social interaction, as well as the restricted and repetitive behaviors, activities and interests, characteristics that must be present early in the development of the child, leading to social, occupational and others (AMERICAN..., 2013).

From the promulgation of the Brazilian Constitution of 1988 (BRASIL, 1988), the first guidelines that give preference to the insertion of people with disabilities within the regular network of education emerged. The term "inclusive education" becomes official from the publication of the National Guidelines for Special Education in Basic Education (BRASIL, 2001).

With the implementation of the National Policy on Special Education in the perspective of Inclusive Education in 2008 and Decree 6571/2008, a change in the way to understand and implement the Specialized Educational Assistance (SEA), which ceases to exist as actions in isolated institutions, replacing regular education, and becoming complementary and supplementary to Regular Education (BRASIL, 2008a, 2008b).

More specifically on the population with ASD, Law 12764 of 2012 established the National Policy for the Protection of the Rights of People with Autism Spectrum Disorder (ASD), in which the person with ASD becomes legally considered a person with a disability (BRASIL, 2012). This law shows coherent guidelines to the proposals of inclusive education, indicating that the attendance to this population is carried out preferentially in the regular schools, and the communities and school teams must be sensitized and qualified to receive and attend this population in their inclusion processes (BRASIL, 2012).

In 2013, the Ministry of Health published two institutional booklets aimed at directing attention to people with ASD in the Unified Health System (SUS): the document 1 called "Guidelines for Attention to Rehabilitation of People with Autism Spectrum Disorder" and the document 2 called "Care Line for Attention to People with Autism Spectrum Disorders and their Families in the Network of Psychosocial Care of the Unified Health System" (BRASIL, 2013a, 2013b).

According to Oliveira et al. (2017), these documents were elaborated in a historical and political context in which there was still no consensus of the positions of members of the field of psychosocial rehabilitation and the members of the rehabilitation field on the best practices to be implemented with this population. Document 1 addresses the disorder as belonging to the field of disability, proposing treatment through rehabilitation; and document 2 recognizes autism as a mental disorder, belonging to the field of psychosocial care. Both documents converge on the fundamental principles related to assistance to the person with ASD, such as the importance of encouraging autonomy, integration in social and daily activities, insertion in the labor market, and inclusion of family members in the care process and respect for singularities. In both documents, the complementarity of psychosocial and rehabilitative interventions is clear (OLIVEIRA et al., 2017).

In a review of the national literature², considering the period between 2008 and 2017, regarding the inclusion of children with ASD in regular education, the results indicated a significant increase in enrollments of these students in the regular education, due to the movements and policies for the paradigm of inclusion. However, these inclusion processes still lack significant qualitative improvements, since the professionals in the schools still have difficulties in their practice with this population, as the lack of knowledge about the characteristics of autism and the lack of specific pedagogical strategies aimed at the improvement in learning (NUNES et al., 2013).

A study by Gomes and Mendes (2010) in Belo Horizonte-MG indicated that students with ASD experience situations of disadvantages when compared with students with typical development, especially in the elementary school grades, in which the gap between pedagogical methods and the promotion of inclusion is more evident. The results also indicated that a great part of the students with ASD is not included in the school grades corresponding to their age group, apparently for failing to meet the criteria required to be raised at school levels.

Another study conducted by Minatel and Matsukura (2015), in a municipality in the State of São Paulo, showed that most children and adolescents with ASD are still enrolled in special schools. The authors argue that the obstacles arise from searching for the guarantee of vacancies in school institutions, a process in which this population suffers discrimination and prejudice, going through aspects related to the poor quality of the offered education, since these spaces have little adequacy and resources necessary to provide an individualized and appropriate teaching in each case, culminating in the lack of guaranty of the student with ASD, especially in regular schools (MINATEL; MATSUKURA, 2015).

The study by Lima and Laplane (2016) conducted in Atibaia-SP, indicated that the process of schooling of people with ASD is mostly closed before completion, with high school dropout rates, with few students who study until the high school, indicating that the laws and guidelines aimed at the school inclusion of this population still do not meet the needs of these students, where there is a guarantee of access, but not of permanence.

In the international literature, studies focused specifically on the adult population with ASD indicate that the prognosis for this population is still unfavorable, since most of the adults with ASD participating in the research have not been able to achieve good levels of independence and social inclusion (LEVY; PERRY, 2011; FARLEY et al., 2009; BILLSTEDT; GILLBERG; GILLBERG, 2011; ANDERSON et al., 2018).

A review by Levy and Perry (2011) about the evolution of people with autism reaching adulthood showed that people with ASD continued to live with their parents or institutions, most of them still very dependent and with very few social relationships beyond family relationships; and the best results were found in people with better development, functioning, and better communication skills.

Still, in this review, the authors highlighted that studies on social prognosis in adolescents and adults with autism have focused on the level of education, employment history, degree of social relationships and independence in daily life. The authors argue that, over the years, there has been an improvement in the prognoses presented by the samples surveyed, which may be directly related to the improvements in policies aimed at this population, such as the inclusion of children with disabilities in regular classes of education and the emergence of specialized services for children with autism. On education, it has been found in these studies that most students with autism drop out of school without formal academic or professional qualifications. Those who complete regular education, employment levels are low, few of them find work, and those entering the market do not have any job stability (LEVY; PERRY, 2011).

A longitudinal study by Farley et al. (2009) in the United States, in which 41 adults with autism were followed up, showed that although the importance of better levels of IQ and language development during childhood for the presentation of better prognoses in adulthood was confirmed, the evolutions were also related to the insertion of the person with ASD in independent life training programs. Five out of the 41 participants were able to study after finishing high school and half of the participants were enrolled in work activities in adulthood. Most individuals with autism in this study participated in educational activities with the aid of special education (a variable that positively influenced the prognosis). The participants also had good support services, including professional rehabilitation services and supplementary income services. However, the authors reported that despite the best prognosis, most of these people with autism still lived with their parents and argue that the good results of this sample may be related to the community in which they are inserted, where the promotion of inclusion of people with disabilities is encouraged and promoted. The authors emphasized the importance of future studies for this population (FARLEY et al., 2009).

Billstedt, Gillberg and Gillberg (2011) carried out research with 108 adult individuals with Autism residing in Gothenburg, Sweden, and sought to analyze the social aspects and quality of life of this population. Interviews were conducted with caregivers, collecting data on the current occupation of these individuals, history of education, services provided, type of accommodation and recreational

activities. All of the adults with ASD from this study had scores that also included them in the category of Intellectual Disability (ID). The results showed that most of them still attend special schools and reside with parents, only one-third of the sample was involved in regular recreational activities, and most of them reported having no friendships. The presence of recreational activities was associated with the best quality of life indexes. The authors discuss the need for improvements in the offer of activities of significant occupation for these adults with ASD and also for the importance of the support offered by the community and by specialized professionals.

A review study by Anderson et al. (2018) with qualitative research on the perception of people involved in the process of transition of people with ASD to adulthood (family members, professionals and the people diagnosed with ASD), showed reports indicating the lack of opportunities for adults with ASD after the high school. The questioned/interviewed individuals indicated the existence of a “mismatch” between the abilities of people with ASD and the demands of higher educational/vocational institutions and possible job openings as causal factors.

Also in this same review study, the authors discussed about the participants’ speeches as factors that can act positively in the adult life of people with ASD, such as the possibility of individualized supports (counselors and coaches) for the person with ASD within the courses and jobs, the possibility of making environmental modifications (adaptations) and a greater community awareness about the specific limitations and potentials of each adult with ASD. The participants of this research also talk about the importance of the existence of integral and individualized services aimed at this population, which do not focus only on the training of the person with ASD, but also be attentive to the changes in environmental, social and physical aspects of these young people, individually, based on person-centered planning, encompassing their family and community (ANDERSON et al., 2018).

Within the perspective of inclusive education, the National Education Policy guides that education and learning systems should guarantee access from early childhood education to higher education, and youth and adult education and professional education are also included in this proposal, as well as complementary actions of special education that

can increase the opportunities for insertion of people with disabilities in their training and insertion in the labor market (BRASIL, 2008c).

Therefore, the need for a greater understanding of the processes of education for people with ASD in Brazil is observed, both in the period of childhood and adolescence and in adulthood.

This study aimed to identify the perspectives considered by the relatives of adults with ASD on the institutions that propose autistic attention in adult life. It also aimed to identify the education course of adults with ASD, the positive aspects and challenges of this experience by their relatives.

2 Method

This is a survey study linked to broader research that involved understanding the demands and daily life of autistic adults and their families³.

A survey was carried out for the objectives of this work that according to Freitas et al. (2000), it is related to obtaining information about characteristics, ideas, opinions, feelings, beliefs of a particular person or group that represent a target population.

2.1 Participants

Sixty-seven families of adults with ASD and living in different regions of Brazil participated in this study. The criteria used to include family members in the study were: being autistic (between 18 and 60 years old) and responsible for their care for at least one year.

2.2 Instruments

Two instruments were used to collect data:

- a) **Identification form:** Form with information about the respondent, the person with ASD and socioeconomic data of the family;
- b) **Questionnaire:** Data collection on social support received, care history (educational assistance, health, and others), the main demands of these adult individuals with ASD and their families. Most of the questionnaire had open questions and some had closed questions. Specifically addressing the purpose of this study, questions addressing the educational processes of people with ASD at various stages of life sought to collect data on:

- The insertion (or not) of the person with ASD in regular or special education institutions in childhood/adolescence and adulthood;
- The participant's description and perception of how was and/or how is the insertion in educational institutions for the person with ASD and for the family at all stages of development;
- What are the needs of the person with ASD who have been and/or are being assisted by these educational institutions?
- What are the needs of the person with ASD who were not and/or still not assisted by these educational institutions?
- What is the opinion of the participants about what educational institutions should be able to receive people with ASD in adulthood?

2.3 Procedures

All ethical procedures were respected and implemented in accordance with Resolution 466/2012 of the National Health Council. After the identification of the institutions and groups linked to autism in adulthood through the global computer network, direct contact was made (through e-mail and/or telephone) with the coordinator of each group and each institution, requesting adherence and cooperation with the study, requesting that they mediate or assist the contact between the researchers and the possible participants, for example in the dissemination of the study and request of contacts of relatives of people with autism in adulthood.

Also, a research of the broader study in which this study is inserted, based on the identification of national institutions that declared that autistic adults were included in their act, carried out as a stage, made contact with 91 of these institutions requesting intermediation with families. Fourteen out of the 91 institutions accepted to participate in the research, mediating the sending and return of research instruments.

The two research instruments were available in print and online format. The kits in print format were sent through the postal service. The instrument kits available in the online format were put on the internet through a free tool from the Google site, called Google Docs. The links to fill out were then

posted through the websites and groups related to the autism theme.

After the data collection was completed, the data were analyzed. The questions as multiple choice formats were organized and analyzed using descriptive statistics. The open questions had their content analyzed through the Collective Subject Discourse (CSD), which consists of the use of operations on verbal materials emerging collective statements, and determining positions and opinions on certain topics. In this technique, the statements are written in the first person singular, which is justified by the Theory of Social Representations (LEFEVRE; LEFEVRE, 2010).

For the operation of the Collective Subject Discourse, Qualiquantsoft Software was used, which acts in the processing of quantitative data (LEFEVRE; LEFEVRE, 2010).

3 Results and Discussions

3.1 The participants

The 67 families of adults with ASD who participated in the study were linked to 14 Brazilian states (Amazônia, Ceará, Federal District, Goiás, Minas Gerais, Mato Grosso do Sul, Pará, Pernambuco, Piauí, Paraná, Rio de Janeiro, Sul, Sergipe, and São Paulo). Most of them live in the state of São Paulo (43.28%). The following table shows more information characterizing the participants in Table 1.

Table 1 shows that 73.13% of the respondents were mothers of people with ASD. In the education level, the highest frequencies were people with complete graduation (27.27%) and people with complete high school (21.21%). Most of the respondents are in the 41-60 age group (71.64%) and 42.62% said they have an income above five minimum wages.

The results presented should be based on the procedures adopted, especially because most of the participants had access to the research tools through the worldwide computer network, in the online format, with a sample that most of them had a higher level of education.

Nevertheless, the expressive number of mothers who are caregivers of their autistic child in this study reinforces evidence from the literature about the participation and accountability of mothers in the care of children with disabilities (SENA et al., 2004; MENDES, 2005; MATSUKURA; MENECHHELLI,

Table 1. Characterization of the research participants.

Characteristics		Frequency (%)
Relationship with the person with ASD	Mother	49 (73.13%)
	Father	7 (10.45%)
	Brother/Sister	6 (8.96%)
	Grandmother/Grandfather	2 (2.99%)
	Husband/wife	2 (2.99%)
	Uncle/Aunt	1 (1.49%)
Education level	Complete Graduation	21 (31.48%)
	Complete High School	14 (21.21%)
	Complete Specialization	13 (19.70%)
	Incomplete Graduation	6 (9.09%)
	Complete Master's/Doctorate	5 (5.58%)
	Incomplete High School	3 (4.55%)
	Incomplete Elementary School	2 (3.03%)
	Complete Elementary School	2 (3.03%)
Age group	From 41 to 50 years old	24 (35.82%)
	From 51 to 60 years old	24 (35.82%)
	From 31 to 40 years old	8 (11.94%)
	More than 61 years old	8 (11.94%)
	From 20 to 30 years old	8 (4.48%)
Current Occupation	Housewives and caregivers of the children	23 (35.94%)
	Education area Professionals	9 (10.06%)
	Retired	4 (6.25%)
	Government workers	4 (6.25%)
	Health professionals	3 (4.69%)
	Students	3 (4.69%)
	Other Professions	10 (28.13%)
Profession	Education area Professionals	17 (26.14%)
	Housewives and Caregiver	12 (18.46%)
	Health Professions	8 (12.31%)
	Students	1 (1.54%)
	Other Professions	24 (36.92%)
Family Income	From 5 to 6 minimum wages	13 (21.31%)
	More than 6 minimum wages	13 (21.32%)
	From 1 to 2 minimum wages	12 (19.67%)
	From 3 to 4 minimum wages	9 (14.75%)
	From 2 to 3 minimum wages	7 (11.48%)
	From 4 to 5 minimum wages	5 (8.20%)
	More than 1 minimum wage	2 (3.28%)

2011; MASUCHI; ROCHA, 2012; SILVA; FEDOSSEB, 2018).

Table 2 shows the data about the characteristics of the person with ASD, focused on this study and linked to the family member.

Twenty-six percent of the people with ASD are between 26 and 30 years old, with Autism as the most frequent diagnosis (74.63%), followed by Asperger's Syndrome, with 14.93%⁴.

3.2 Insertion in educational institutions in the period of childhood and adolescence

When participants were asked about the educational institutions attended by the person with ASD during the period of childhood and adolescence, 88.06% reported that their child/relative was enrolled in educational institutions during this period, while 11.94% did not answer to this question.

Table 2. Description of people with ASD.

Characteristics		Frequency (%)
Current age	From 26 to 30 years old	18 (26.87%)
	From 18 to 20 years old	16 (23.88%)
	From 21 to 25 years old	16 (23.88%)
	From 31 to 35 years old	10 (14.93%)
	From 36 to 41 years old	7 (10.45%)
Gender	Man	51 (76.12%)
	Woman	16 (23.88%)
Diagnosis	Autism	50 (74.63%)
	Asperger's syndrome	10 (14.93%)
	Global Developmental Disorder	5 (7.46%)
	Unknown	2 (2.99%)

Most of the people with ASD were enrolled in special schools (38.98%), followed by those who were enrolled in special and regular schools (33.90%) and those enrolled only in regular schools (27.12%), with most of them attending only the period of pre-school education (N = 13) and some attending higher education.

When discussing the school period experienced by the autistic family during childhood and adolescence, the gains from this school insertion were detailed by some families. However, the difficulties faced for the permanence of the autistic children in the school were also registered like experience shared by the relatives.

The CSD below shows the opinion of family members who felt that the early childhood period was a good time, with gains for the development of their children.

The school period was good, it was good, with a slow recovery and a good improvement of F, at first he did not accept, but over time he began to like school, that period was very important and helped a lot in his development and independence from day to day, it was very helpful. In addition to learning to read, write, and color, it was important as he became more socialized, with the opportunity to live with people of the same age without the autistic spectrum, I could then insert my child in various environments; in short, he learned to socialize, he developed writing, he improved ADL, he became somewhat independent, knowing how to be alone. The first school was important because it stimulated him early, the second was extremely important because it was there that he developed in the motor, sensory part, in school he learned hygiene habits, practiced different activities (capoeira, painting, music, and activities in the computer) and developed their affective side, the

teachers were very attentive and caring, it was a period of much learning in terms of coexistence and acceptance as well (CSD-A).

The CSD-B, CSD-C, CSD-D below illustrate the reality described by the family members regarding the different difficulties found.

My son got the job when he was 11, and he already had a self-injurious situation, and the professionals did not have the resources to develop an effective job, he suffered a great deal of prejudice and discrimination and he was several times asked to be out of the various schools they spent, on average, a year in each school (CSD-B).

Some participants in their speeches said that the difficulties were related to the characteristics of the person with ASD, their limitations, difficulties, and behaviors, as observed in the following CSD:

It was a time that was not cool, he did not like school, going to school was not enjoyable, he had difficulty understanding what was expected of him, and did not respond to positive or negative stimuli, good or bad, so much; he had difficulty in learning and did not follow the content given in the classroom due to dysgraphia, he had difficulty at the beginning because he could not cover the lyrics correctly and did not paint well, and in physical education he had no coordination to accompany colleagues, I believe the period was positive, but the aggressive behavior prevented in the continuity of the activities, because it was very problematic, he did not interact, he was isolated, he did not like shouting and cried a lot (CSD-C).

Participants also highlighted in their speeches their perceptions about the difficulties related to the limitations of educational institutions and society, such as lack of dialogue between the school and the

family, lack of knowledge and lack of preparation of institutions and school professionals, lack of structure and difficulties in the process of inclusion in regular schools, as observed in the following CSD:

The school period was difficult, with many barriers, it was good, but at the same time, we were anxious due to complaints and problems not resolved very clearly. At first, we felt impotence due to lack of knowledge and financial conditions for hiring professionals to provide psycho-pedagogical support and other activities. In some schools, the feeling was bad as I felt that the place was not very good, on the other hand, I needed a place to leave him during the day so I could work. Thus, these were always periods of great stress, thanks to the little or no knowledge of the schools in dealing with the daily difficulties and challenges that F. presented. We regret that in his time there was no inclusion system, one of the greatest challenges in private schools was with the term and realization of "inclusion". In a couple of schools, we were asked to pay a "nanny" to monitor him, which in practice made him more isolated from other students. These aspects, when perceived by my family, caused a great erosion in the relation with the direction of the school and the teachers; because although it was talked about every work process that the school offered, it did not meet, which caused wear and tear on each... I believe that the disrespect and disregard that some professionals demonstrated when receiving information from the family made it difficult the family-school relationship. For me, in particular, it was very exhausting, in general, at the beginning of the year, the teacher told me that my son had a "problem", that I was looking for a special school. I insisted that he was perfectly capable of learning the contents. I always had the conviction that the best thing for him was the regular school. The school wants to live up to the family's money (extra fee and extra staff) to accompany the student, while the family expects an effective result and not "masked" tasks/activities. it was also a time of great insecurity as the mothers of the other children were reluctant to accept my son at school, which created discomfort. The win was to challenge, year after year, this highly exclusive socio-educational system (CSD-D).

The speeches also showed the efforts and initiatives of the family members in obtaining gains in development in learning for their children, such as adaptations, reinforcement and activities carried out at home and the search and application of new knowledge for autistic learning, as presented in CSD-E:

In general, he achieved regular academic results, with some effort by us, also developed a complete ADL, but based on the sum of aids, including at home, because, at home, my partner and I gave reinforcement daily and intense. For us, in the family, the challenges were to study, seek to know methodologies for applicability, where there were gains for him and others that I can at the moment help (CSD-E).

To discuss the literature on school inclusion policies, it should be pointed out that the sample studied is within the age group from 18 to 41 years old, born between 1971 and 1995, a period of intense changes in policies and the realities of people with disabilities.

Considering the period of two decades, from 1970 to 1990, the first federal policy body for students with disabilities was created in 1973 called the National Center for Special Education (CENESP). From 1981, known as the "International Year of People with Disabilities", goals are set that will underpin Brazilian public inclusion policies; and in 1994, the World Conference on Special Educational Needs to be promoted by the United Nations Educational, Scientific and Cultural Organization (UNESCO), culminated in the elaboration of the "Declaration of Salamanca", which documents the movement for the inclusion of people with disabilities (OLIVEIRA, 2011).

The results of this study reveal that most of the respondents were in regular education only during the period of infantile education, which can illustrate the reality within the historical context about the inclusion of children and adolescents with ASD in schools.

There were reports among the speeches that the insertion in schools in the period of childhood and adolescence provided gains for the development of the person with ASD, which may reinforce considerations in the literature, where sharing between school and families, in the responsibility of educating may allow these families to visualize the real potentialities and possibilities of the child with ASD (WELBER; SILVA, 2006).

An important point to be discussed for the results obtained here are those in which the family members reported that the difficulties experienced in the childhood and adolescence school period were directly related to the limitations of the person with ASD, such as their difficulties in behavior, exempting the educational system of responsibilities from the difficulties and failures of this period.

These results discuss and reinforce considerations in the theoretical study of Serra (2008) that discusses the conception of society and also assumed by the family members about the person with the disability, a conception that still places the limitation in front of the human condition of the subjects (who have basic needs like any other person), which expresses the level of rootedness of such premises, and demonstrates the necessity that such conceptions be worked culturally, so they are replaced and referring to the implication of society in the changes necessary to implementation of inclusive actions.

The speeches of the difficulties faced by the family indicated the lack of preparation of the professionals to deal with the difficulties of the person with ASD and the difficulty in keeping the children in the schools due to the lack of school resources. These aspects have been observed in the literature and still appear to be present in the processes of school inclusion (CAMARGO; BOSA, 2009; COSTA, 2012).

In the review carried out by Camargo and Bosa (2009), that the inclusion of people with disabilities requires efforts in the restructuring and adaptation of curricula and resources mainly focused on the cases of children with significant deficits; and there are still few children with ASD included in the regular education system, due to the lack of preparation of professionals for the demands arising from this inclusion, demonstrating the need for greater investments in the area.

The inclusion of school support professionals, as facilitators and mediators, the adaptation of routines and curricula to the individual needs of the students with ASD, the interdisciplinary partnership and the Collaborative Consulting are among the initiatives that can contribute positively to the processes of inclusion of students with ASD in the regular network of education, presented by public policies and the national literature of the area (MOUSINHO et al., 2010; BARBA; MINATEL, 2013; BRASIL, 2015; APORTA; LACERDA, 2018; CAMPOS; SILVA; CIASCA, 2018).

The Brazilian Law on Inclusion of the Person with Disabilities indicates the inclusion of other professionals in the context of inclusive education, such as the insertion of a school support professional, who would be responsible for supporting this disabled student in his various activities within the school environment (such as hygiene, locomotion, feeding and other things the child needs support) (BRASIL, 2015).

When dealing with the school inclusion of students with ASD, each case is a unique case, with their individual and peculiar demands, which must be evaluated as they are worked according to their individual demands and potentialities. Children should always be compared to themselves, and all the professionals involved should work in consonance and be aware of these singularities, stimulating the development of autonomy and motivation of the person with ASD (MOUSINHO et al., 2010).

In this sense, Aporta and Lacerda (2018), when conducting a case study about the inclusion of a child with ASD in the second year of elementary school, found in their results that the daily realization of adjustments by the teacher to the individual educational needs of this student have provided positive results to their learning and pedagogical development.

Also, it is important to emphasize the importance of interdisciplinary work in the processes of school inclusion of people with ASD, with therapeutic projects aligned to pedagogical projects, actions that, although not yet so frequent in Brazilian school inclusion, are pointed as promising to contribute positively with the development of social and cognitive skills of people with ASD (CAMPOS; SILVA; CIASCA, 2018).

In the participation of the occupational therapist in the processes of inclusion, Jurdi, and Amiralian (2006) based on Winnicottiana theory, presented a study on the use of play activities as a way of approaching children with special educational needs and children with typical development. In this study, not only the environmental transformations but also the individual issues of the disabled child and the interaction models, in this experience, the presence of the occupational therapist provided a re-signification of the role of people with disabilities within this context, no longer as a person destined to failure, but as a creative and potential subject.

Barba and Minatel (2013) showed the possibility of contribution of the occupational therapist in the processes of inclusion of students with ASD in the regular network of education, through the method called Collaborative Consulting, improving the quality of care for children with ASD, involving actions and orientations with the child, the family and the school team, focusing on the identification of needs and the elaboration of action projects in a dynamic and horizontal way, together with the professionals of the school where the inclusion process takes place. The reported experience shows

that the implementation of collaborative counseling contributes positively to the inclusion and permanence of the child with ASD in the regular educational network (BARBA; MINATEL, 2013).

The Collaborative Consulting can also be part of the curricular adaptation processes for students with ASD, so the school teams can count on the support and interdisciplinary support in the elaboration and adaptation of their curricula. A bibliographic review by Silva-Porta et al. (2016), investigating publications of the annals of the Brazilian Congress of Special Education on the curricular adaptation, in the scope of the regular educational institutions, indicated that there are still a few publications on the subject, being that predominant focus of the publications is adapted to the Portuguese language subject; the authors emphasize that adapting curricula is not about creating a new curriculum, but about making it more dynamic so it can address the need of all students.

3.3 Insertion into educational institutions in adulthood

Participants were asked about the educational institutions they were/are attending by the person with ASD in adulthood. Among the participants, 58.21% (N = 39) reported that their son/relative was enrolled in educational institutions during this period, while 41.79% (N = 28) did not respond to this question.

Most of the people with ASD who attend educational institutions in adulthood are or were exclusively enrolled in special schools (71.79%), followed by people attending/attended regular and special schools concomitantly (25.64%) and only 2.56% attend/attended regular education exclusively.

The respondents were also questioned about the needs of the person with ASD in adulthood who are attended by these educational institutions, and the results indicated that most are demands related to socialization and leisure (N = 20), followed by multidisciplinary therapies (N = 11) and activities to improve autonomy (N = 8).

When asking about the need to be attended by these educational institutions, the respondents indicated the demands for multidisciplinary therapies (N = 34), followed by activities of professionalization (N = 12) and socialization and leisure activities (N = 9).

The CSDs on the perspectives on educational institutions for adults with ASD present general aspects about how these institutions should work,

indicating the importance of integrated care to the individual with ASD and full-time, offering therapies, physical activities, cultural, leisure, and socialization, as seen in the following CSD-F:

The dream would be a full-time institution where they seek to develop the autistic, occupy their time, and develop their potential according to their capacity. The physical space should be broad, an autistic, educational and special institution that is socio-pedagogical-therapeutic, or an assisted residence where they stay all day returning at night to their homes. It should be full time, with 1 caregiver for each 6-hour period. They should also separate students by age, by grade and physical strength, foster parenting and organize outside activities; it should have a differentiated and well-structured study and offer differentiated care according to the field and interest of the person. These institutions should not be just a place to stay, but to occupy time in a useful way, I think that besides multidisciplinary care, it would be good to have recreation activities, festivities, animal therapies, music lessons, with physical activities, walking, judo, dance, theater, choral, classrooms with contents adapted to the language/communication of the group, literacy, leisure, cultural activities... that stimulate the interaction between young people with and without autism, that is, within the area of their interests, in addition to group living, which is very important. Also, I am sympathetic to the use of ever-increasing technology in teaching and mentoring. It is a completely utopian model of education for Brazil, but it is my opinion... Initially, it would be in an integral regime and then, reducing the workload according to evolution. Of course, it is necessary to work the yes and no and that is difficult for the autistic and to always schedule the change in the routine, so limits and discipline must be imposed so the space of the "other" is respected (CSD-F).

Another indication is the importance that these institutions involve not only people with ASD but also the whole family, offering guidance and family-oriented groups, as seen in the following CSD-G:

It is necessary to involve families in these projects; it occurs that the disinformation hurts the whole family and harms everyone, these institutions should offer professionals to guide families, provide guidance to parents on how to proceed with the person in case of crisis and provide psychological support to the family through study groups and therapy. Also, support groups for family members who live with these people on a daily basis, besides promoting family and social interaction (CSD-G).

Participants also reported that the educational institutions for adults with ASD should have the professional focus in their planning, according to the capacities and interests of each individual, offering preparation and opportunity for their insertion in the labor market, as observed in the CSD-H:

Besides to the pedagogical part, it should also prepare for work, the educational institution should turn to the professionalization of these adults to be able, as much as possible, to sustain them or rather to feel useful. In my opinion, depending on the commitment of autistic professionals should be working on, I think it is fundamental that, in cases where this is possible, they are prepared for the work environment, my child's greatest difficulty today is, in my opinion, his professional life. So, I believe there should be a work-oriented, vocational focus to prepare the youth with work-oriented activities, which leads to some branch, offering professional training and job opportunity (CSD-H).

Considering the rarity of the scope of opportunities of this population for regular education and higher education, a complementary analysis was carried out, which resulted in the focused characterization of these autistic individuals whose family members participated in the research, as shown in Table 3.

Table 3 shows that most of the eight participants who were/are enrolled in regular education in the period of adulthood had Asperger's Syndrome (N = 5); with respect to the severity level, there is no preponderance of any of the levels⁵.

Table 3 shows that the most of the adults with ASD were or are enrolled in higher education institutions (N = 5), followed by those who were or are enrolled in high school and EJA (N = 3).

Of the sample of this research 58.21% still attend educational institutions in adult life, mainly institutions of special education. This result reflects

the reality of exclusion suffered by people with special educational needs who have experienced a transitional period in the legislation focused on special education in Brazil.

Only eight of the participants of this research were able to attend regular educational institutions in the period of adulthood, in which six attended or attend universities, a still small number, emphasizing that the sample presented here is a plot of the population that mostly have good socioeconomic conditions and access to support services.

In the international literature, studies also indicate a very small number of adults with ASD who were able to continue their studies beyond primary and secondary education. In those cases in which these subjects can complete the stages of regular education, after leaving the educational system, are still experiencing difficulties in entering the labor market and the ones who enter the formal market have jobs with low wage rates and positions that do not offer stability (HOWLIN et al., 2004; FARLEY et al., 2009; LEVY; PERRY, 2011).

When dealing with the insertion of adult students with ASD in special educational institutions, the participants of this study reported in their speeches that they are satisfied with these institutions, since these devices provide their children/relatives with possibilities of socialization. However, these respondents indicate that it would be necessary for these institutions to offer multidisciplinary therapies and vocational training to the child with autism, similar to the international literature that shows the importance of the existence of intervention programs for the transition to adulthood (HENDRICKS; WEHMAN, 2009; RYDZEWSKA, 2012; CARTER et al., 2013).

When asked about their educational perspectives of the child/relative with ASD for adulthood, the

Table 3. Research participants who attended/attend Regular Schools in adulthood.

Subject	Diagnosis	Severity Level	Type of regular teaching institution attended in adult life
1	Asperger's syndrome	-	Completed college
2	Autism	Severe	Attended university
3	Asperger's syndrome	Mild	Attended University (Physical Education)
4	Asperger's syndrome	Severe	Concluded his law school
5	Asperger's syndrome	Moderate	Attended university (Publicity) and now does postgraduate
6	Asperger's syndrome	-	Regular schools (completed high school)
7	Autism	Mild	Regular schools (finishing high school)
8	TID	Moderate	Attended the EJA

TID = Invasive Developmental Disorders; EJA = Youth and Adult Education.

participants showed speeches that encompass the need for the presence of professionals from multiple areas and these professionals have the training and qualifications that enable them to work with this audience. Also, the need for these institutions to work not only with people with ASD was indicated but also encompasses the whole family, providing information, guidance and support actions for them.

The Operational Guidelines for Educational Assistance Specialized in Basic Education bring contents and recommendations that dialogue about the role of specialized institutions in the inclusion, so the concept of Special Education presented here surpasses the substitutive vision of Special Education to Common Teaching. The guideline is that these services in Specialized institutions be understood and arranged as allies to the regular educational institutions and contribute effectively in guaranteeing the access of the students to the common education, offering services and supports that complement the formation of these students (BRASIL, 2013c).

However, authors such as Mantoan and Prieto (2006) discussed the difficulty in interpreting the role of specialized institutions in the current inclusion process, in front of which the regular educational system has to offer an inclusive quality learning environment. In this context, these specialized educational institutions present as complementary devices to regular education, or as substitute devices, in cases where the regular school does not have the possibility to offer the necessary structure for the inclusion of certain people with special educational needs. Such considerations are important and should guide the debate about the role of specialized institutions. However, there is also the fact that large numbers of adult children with autism are absolutely deprived of any possibility of insertion in these services.

The results obtained from the speeches of the participants of this study contributed to the literature of the area when pointing out important questions regarding the needs of people with ASD:

- The need for integral care, encompassing not only the pedagogical area but also the social and therapeutic area;
- The importance of individualized planning, for the development of the potential of each of the subjects, with activities also in the recreational and cultural area;

- The need for physical infrastructure and human resources capable of accommodating the diverse needs of people with ASD;
- Providing full-time support to families who need this support.

By focusing on the inclusion of adults with ASD in educational institutions, there is a population that has been for a long time outside the educational system, with numerous losses that have been added over time, reflected in a significant reduction in the possibilities of social inclusion in the period of adult life.

4 Final Considerations

This study aimed to present reports and perspectives of parents and caregivers of adults with ASD on the educational process of their child/relative in different stages of life, both in regular educational institutions and in special institutions.

Regarding the education level in the period of childhood and adolescence, most of them attended regular schools and special schools concomitantly. The insertion in regular education happened for most of them, but only in the initial years. Relatives reported that this period was a period of gains for the person with ASD, however, they pointed out that it was also a period of challenges and apprehension, with difficulty of access and permanence in these schools and experience of situations of prejudice and social barriers.

In adulthood, most of these individuals were and/or are still enrolled in special educational institutions, and only a very small portion of adults with ASD remained in regular education. Educational perspectives for adult life were revealed, in which participants sought places for coexistence, multidisciplinary therapies, host families, professionalization activities for adults with ASD, individualized care and the presence of qualified professionals.

Among the limits of this study is that it has a differentiated sample of participants since a large portion presents complete higher education level and indicate different economic conditions of the majority of the Brazilian population. Moreover, such a sample already has a differential when being inserted in institutions or groups related to ASD. Nevertheless, because they already integrate these services, they gather experiences and a critical sense about the needs of advancement. Thus, the importance of future studies capable of including

new samples of participants is highlighted to characterize different realities.

Acknowledgements

Graduate Program in Special Education – UFSCar, *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES) and *Conselho Nacional de Desenvolvimento Científico e Tecnológico* (CNPq).

REFERENCES

- AMERICAN PSYCHIATRIC ASSOCIATION – APA. *Manual Diagnóstico e Estatístico de Transtornos Mentais (DSM-IV-TR)*. Porto Alegre: Artmed, 2002.
- AMERICAN PSYCHIATRIC ASSOCIATION – APA. *Manual Diagnóstico e Estatístico de Transtornos Mentais (DSM-V)*. Porto Alegre: The Art of Medication, 2013.
- ANDERSON, K. A. et al. Transition of individuals with autism to adulthood: a review of qualitative studies. *Pediatrics*, Burlington, v. 141, p. 318-327, 2018. Supplement 4.
- APORTA, A. P.; LACERDA, C. B. F. Estudo de caso sobre atividades desenvolvidas para um aluno com Autismo no Ensino Fundamental. *Revista Brasileira de Educação Especial*, Bauru, v. 24, n. 1, p. 45-58, 2018. <http://dx.doi.org/10.1590/s1413-65382418000100005>.
- BARBA, P. C. S.; MINATEL, M. M. Contribuições da terapia ocupacional para a inclusão escolar de crianças com autismo. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 21, n. 3, p. 601-608, 2013. <http://dx.doi.org/10.4322/cto.2013.062>.
- BILLSTEDT, E.; GILLBERG, I. C.; GILLBERG, C. Aspects of quality of life in adults diagnosed with autism in childhood. *Autism*, London, v. 15, n. 1, p. 7-20, 2011. <http://dx.doi.org/10.1177/1362361309346066>. PMID:20923888.
- BRASIL. Constituição da República Federativa do Brasil. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 5 out. 1988.
- BRASIL. Ministério da Educação. *Diretrizes nacionais para a educação especial na educação básica*. Brasília, 2001.
- BRASIL. Decreto nº 6.571, de 17 de setembro de 2008. Dispõe sobre o atendimento educacional especializado, regulamenta o parágrafo único do art. 60 da Lei nº 9.394, de 20 de dezembro de 1996, e acrescenta dispositivo ao Decreto nº 6.253, de 13 de novembro de 2007. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 17 set. 2008a.
- BRASIL. Ministério da Educação. Secretaria de Educação Especial. *Política nacional de educação especial na perspectiva da educação inclusiva*. Brasília, 2008b. Disponível em: <portal.mec.gov.br/arquivos/pdf/politicaeducespecial.pdf>. Acesso em: 1 jan. 2018.
- BRASIL. *Política nacional de educação especial*. Brasília: MEC/SEESP, 2008c.
- BRASIL. Lei nº 12.764, de 27 de dezembro de 2012. Institui a Política Nacional de Proteção dos Direitos da Pessoa com Transtorno do Espectro Autista; e altera o § 3o do art. 98 da Lei no 8.112, de 11 de dezembro de 1990. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 27 dez. 2012.
- BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. *Linhas de cuidado para a atenção às pessoas com Transtornos do Espectro do Autismo e suas famílias na Rede de Atenção Psicossocial do SUS*. Brasília, 2013a.
- BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. *Diretrizes de atenção à reabilitação da pessoa com Transtornos do Espectro do Autismo*. Brasília, 2013b.
- BRASIL. *Diretrizes curriculares nacionais gerais da educação básica*. Brasília, 2013c.
- BRASIL. Lei nº 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 6 jul. 2015.
- CAMARGO, S. P. H.; BOSA, C. A. Competência social, inclusão escolar e autismo: revisão crítica da literatura. *Psicologia e Sociedade*, Belo Horizonte, v. 21, n. 1, p. 65-74, 2009. <http://dx.doi.org/10.1590/S0102-71822009000100008>.
- CAMPOS, C. C. P.; SILVA, F. C. P.; CIASCA, S. M. Expectativa de profissionais da saúde e de psicopedagogos sobre aprendizagem e inclusão escolar de indivíduos com transtorno do espectro autista. *Revista Psicopedagogia*, São Paulo, v. 35, n. 106, p. 3-13, 2018.
- CARTER, E. W. et al. Connecting youth and young adults with autism spectrum disorders to community life. *Psychology in the Schools*, Brandon, v. 50, n. 9, p. 888-898, 2013. <http://dx.doi.org/10.1002/pits.21716>.
- COSTA, H. P. F. *O autismo e as respostas educativas na escola pública*. 2012. 149 f. Dissertação (Mestrado em Educação Especial) – Escola Superior de Educação Almeida Garrett, Lisboa, 2012.
- FARLEY, M. A. et al. Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, Hoboken, v. 2, n. 2, p. 109-118, 2009. <http://dx.doi.org/10.1002/aur.69>. PMID:19455645.
- FREITAS, H. et al. O método de pesquisa Survey. *Revista de Administração*, São Paulo, v. 35, n. 3, p. 105-112, 2000.
- GOMES, C. G. S.; MENDES, E. G. Escolarização inclusiva de alunos com autismo na rede municipal de ensino de Belo Horizonte. *Revista Brasileira de Educação Especial*, Bauru, v. 16, n. 3, p. 375-396, 2010. <http://dx.doi.org/10.1590/S1413-65382010000300005>.
- HENDRICKS, D. R.; WEHMAN, P. Transition from school to adulthood for youth with autism spectrum disorders

- review and recommendations. *Focus on Autism and Other Developmental Disabilities*, Georgia, v. 24, n. 2, p. 77-88, 2009. <http://dx.doi.org/10.1177/1088357608329827>.
- HOWLIN, P. et al. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, Oxford, v. 45, n. 2, p. 210-229, 2004.
- JURDI, A. P. S.; AMIRALIAN, M. L. T. M. A inclusão escolar de alunos com deficiência mental: uma proposta de intervenção do terapeuta ocupacional no cotidiano escolar. *Estudos de Psicologia*, Campinas, v. 23, n. 2, p. 191-202, 2006. <http://dx.doi.org/10.1590/S0103-166X2006000200009>.
- LEFEVRE, F.; LEFEVRE, A. M. C. *Pesquisa de representação social: um enfoque qualitativo: a metodologia do discurso do sujeito coletivo*. Brasília: Líber Livro Editora, 2010.
- LEVY, A.; PERRY, A. Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*, London, v. 5, n. 4, p. 1271-1282, 2011. <http://dx.doi.org/10.1016/j.rasd.2011.01.023>.
- LIMA, S. M.; LAPLANE, A. L. F. Escolarização de alunos com autismo. *Revista Brasileira de Educação Especial*, Marília, v. 22, n. 2, p. 269-284, 2016. <http://dx.doi.org/10.1590/S1413-65382216000200009>.
- MANTOAN, T. E.; PRIETO, R. G. *Inclusão escolar: pontos e contrapontos*. São Paulo: Summus, 2006.
- MASUCHI, M. H.; ROCHA, E. F. Cuidar de pessoas. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 23, n. 1, p. 89-97, 2012.
- MATSUKURA, T. S.; MENECHIELI, L. A. Família de crianças autistas: demandas e expectativas referentes ao cotidiano e cuidados e ao tratamento. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 19, n. 2, p. 137-152, 2011.
- MENDES, P. B. M. T. Quem é o cuidador? In: DIAS, E. L. F.; WANDERLEY, J. S.; MENDES, R. T. (Org.). *Orientações para cuidadores informais na assistência domiciliar*. Campinas: UNICAMP, 2005. p. 19-33.
- MINATEL, M. M.; MATSUKURA, T. S. Familiares de crianças e adolescentes com autismo: percepções do contexto escola. *Revista de Educação Especial*, Santa Maria, v. 28, n. 52, p. 429-442, 2015.
- MOUSINHO, R. et al. Mediação escolar e inclusão: revisão, dicas e reflexões. *Revista Psicopedagogia*, São Paulo, v. 27, n. 1, p. 92-198, 2010.
- NUNES, D. R. P.; AZEVEDO, M. Q. O.; SCHIMIDT, C. Inclusão educacional de pessoas com Autismo no Brasil: uma revisão da literatura. *Revista de Educação Especial*, Santa Maria, v. 26, n. 47, p. 557-572, 2013.
- OLIVEIRA, B. D. et al. Políticas para o autismo no Brasil: entre a atenção psicossocial e a reabilitação. *Revista de Saúde Coletiva*, Rio de Janeiro, v. 27, n. 3, p. 707-726, 2017.
- OLIVEIRA, J. B. G. A perspectiva da inclusão escolar da pessoa com deficiência no Brasil: um estudo sobre as políticas públicas. *Revista Tempos e Espaços em Educação*, São Cristóvão, v. 6, p. 147-159, 2011.
- RYDZEWSKA, E. Destination unknown? Transition to adulthood for people with autism spectrum disorders. *British Journal of Special Education*, London, v. 39, n. 2, p. 87-93, 2012. <http://dx.doi.org/10.1111/j.1467-8578.2012.00536.x>.
- SENA, R. et al. O cotidiano da cuidadora no domicílio: desafios de um fazer solitário. *Cogitare Enfermagem*, Curitiba, v. 11, n. 2, p. 124-132, 2004.
- SERRA, D. *Entre a esperança e o limite: um estudo sobre a inclusão de alunos com autismo em classes regulares*. 2008. 127 f. Tese (Doutorado em Psicologia Clínica) – Pontifícia Universidade Católica, Rio de Janeiro, 2008.
- SILVA, R. S.; FEDOSSEB, E. Perfil sociodemográfico e qualidade de vida de cuidadores de pessoas com deficiência intelectual. *Cadernos Brasileiros de Terapia Ocupacional*, São Carlos, v. 26, n. 2, p. 357-366, 2018. <http://dx.doi.org/10.4322/2526-8910.ctoAO1220>.
- SILVA-PORTA, W. C. et al. Perfil dos estudos feitos sobre adaptação curricular no âmbito da escola regular. *Revista de Educação Especial*, Santa Maria, v. 29, n. 54, p. 215-231, 2016.
- WELBER, V. B.; SILVA, R. N. As práticas de cuidado e a questão da deficiência: integração ou inclusão? *Estudos em Psicologia*, Campinas, v. 23, n. 1, p. 29-37, 2006.

Author's Contributions

Fernanda Duarte Rosa responsible for research, text design, organization of sources and analyzes, text writing and review. Thelma Simões Matsukura responsible for the guidance of the research, text design, analysis, text writing, and review. Carolina Elisabeth Squassoni responsible for contributing to the analysis of the data and text review. All authors approved the final version of the text.

Funding Source

PhD research funded by *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES)* and supported by the *Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq)/Edital Universal*.

Notes

- ¹ This is part of a PhD research carried out in the Graduate Program in Special Education of UFSCar: “Autistic adults and their families: available resources and demands of daily life”. Study submitted and approved by the Human Research Ethics Committee of UFSCar, under the number CAAE: 00908812.3.0000.5504, opinion nº 177.789.
- ² Bibliographic review carried out from 2008 to 2017 at Scielo, VHL and also in the Thesis and Dissertation Banks of the Universities: UNESP, UFSCar, USP and Unicamp. The descriptors “autism” and “education” were used.
- ³ PhD research carried out in the Graduate Program in Special Education of UFSCar called “Autistic in adulthood and their families: resources available and demands of daily life”.
- ⁴ The nomenclature used at the beginning of this research used as reference base DSM IV (AMERICAN..., 2002), which addressed Autism Spectrum Disorders according to the subdivision in: Autism, Asperger’s Syndrome and Global Developmental Disorders without any other specification.
- ⁵ This question was presented to the interviewees as an open question, enabling the freedom to use terms and to refrain from answering.