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ORIGINAL ARTICLE

Are we truly listening to families? Are we managing to be partners with these families of children and adolescents with Autism Spectrum Disorder?

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Abstract

Although the prevalence of Autism Spectrum Disorders (ASD) is high and the topic is relevant, Brazilian literature on the subject is scarce. **Objective:** To characterize aspects concerning the diagnosis of ASD in children and adolescents in an outpatient pediatric primary care health unit. **Methods:** A retrospective, descriptive, exploratory study, with data collected from medical records of children/adolescents diagnosed with ASD in a medical school outpatient pediatric primary care health unit, partnered with SUS between February 2023/May 2024. **Results:** The sample consisted of medical records of 291 children and adolescents. The mean age was 82.5 ± 43.9 months (21-206). Caregivers/family suspected ASD in 84% (199/237) and the daycare/school in 28.5% (83/128). The most frequent reason for the first consultation was clinical/routine complaints in 32.5% (94/289), followed by suspicion of ASD/Autism in 15.6% (45/289). The most frequently reported symptoms were those related to behavior in 10.4% (30/289). The age of onset of symptoms was 29.5 ± 21.9 months. The age of diagnosis was 63.2 ± 39.7 months. There was no previous diagnosis in 33.7% (97/288). **Conclusion:** The gap between caregivers perception of first symptoms and the age of diagnosis underscores the importance of screening for ASD. Furthermore, as many caregivers suspect ASD and do not express their concerns, it is essential to improve professional education on empathy and building trust between families and pediatricians.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is defined, according to the *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5)*, as persistent deficits in social communication and social interaction across multiple contexts, in addition to exhibiting restricted and repetitive patterns of behavior, interests, or activities. These characteristics must be present early in the developmental period and must cause clinically significant impairment in social functioning. They should also not be primarily attributable to intellectual disability or global developmental delay, although comorbidity with the former may occur[1].

The estimated prevalence of ASD in 2020 was 1 in every 36 children aged 8 years[2]. Among 4-year-old children, the estimated prevalence is 21.5 per 1,000 U.S. children[3]. The growth in early identification, changes toward broader diagnostic criteria, and intensified developmental surveillance coincide with the increase in prevalence[4].

Since 2006, the American Academy of Pediatrics (AAP) has recommended that all children be screened for ASD, particularly at 18 and 24 months of age, as well as routine developmental surveillance during pediatric visits[5]. In Brazil, in 2005, the Ministry of Health (MS) created the *Child Health Handbook* (replacing the *Child Card* created in 1974), establishing an instrument for monitoring child development to be completed by healthcare professionals. This instrument includes monthly records of development and behavior up to 36 months, and later editions expanded these records to monthly entries up to 60 months and annual entries up to 9 years[6–8]. Additionally, the handbook includes warning signs for ASD and guidance for healthy development, with sections for families and caregivers, as well as healthcare professionals.

In 2013, the Ministry of Health published the *Guideline for the Care and Rehabilitation of Individuals with ASD*, aimed at supporting early identification in children up to 3 years old[9]. In 2017, the Brazilian Society of Pediatrics (SBP) published its first scientific document on ASD, and the instrument *Modified Checklist for Autism in Toddlers (M-CHAT-R)* was validated and translated into Brazilian Portuguese in 2008[10,11]. In 2024, the SBP released two additional scientific documents regarding ASD diagnosis[12,13].

Due to the high prevalence of ASD, the broader dissemination of information about the disorder and its symptoms, and the pediatrician's key role as the first line of care for children and adolescents, the pediatrician becomes a fundamental component in the strategy for early identification and access to intervention services. The goal is early detection to achieve a better prognosis[14].

According to data from the Outpatient Information System (SAI) of the Ministry of Health, 9.6 million outpatient visits were provided to individuals with ASD in 2021, of which 4.1 million were for children up to 9 years of age[15]. These numbers highlight the importance of understanding the population served by healthcare professionals. Such knowledge would provide a broader and deeper view not only of the Brazilian context but also of the specific reality of each service, enabling not only better practices during consultations (observing key aspects of the history, physical examination, and family approach, among others) but also the development of public health policies with proposals and treatments that avoid bottlenecks in care. However, the literature on this topic within the Brazilian context is scarce[16].

The objective of this article is to contribute to this body of knowledge by characterizing aspects related to the diagnosis of ASD in children and adolescents seen at the Pediatric outpatient clinic of a primary care unit in a medical teaching institution in Rio de Janeiro (RJ).

METHODS:

This is a retrospective, descriptive, exploratory study of diagnoses of ASD, autism, childhood autism, or Pervasive Developmental Disorder (PDD) in children and adolescents (0 to 18 years old) seen at the Pediatric outpatient clinic of the Souza Marques Medical School primary care unit, Itanhangá campus, in the city of Rio de Janeiro (RJ), from February 1, 2023 (when the electronic medical record system was implemented) to June 30, 2024. Data were collected from electronic medical records using a search system with the following keywords: "autismo," "autismo infantil," "transtorno do espectro autista," "transtorno global do desenvolvimento (TGD)," and the corresponding codes of the International Classification of Diseases – 10th revision (ICD-10).

A search of physical medical records was also conducted for patients previously followed in this outpatient clinic who were seen during the study period. The number of the physical record is listed in the electronic system. All records of children and adolescents (0 to 18 years of age) with a diagnosis of ASD or PDD (the latter due to the change in diagnostic grouping and terminology from DSM-IV to DSM-5) or autism, and who were seen during the study period, were included. Records that were incomplete or left unfilled were excluded.

The pediatric outpatient clinic at the Itanhangá Unit is a primary care clinic that provides free services without territorial restrictions and includes a pediatric neurologist, a child psychiatrist, a developmental pediatrician, among other specialties. Evaluation by these specialists occurs in a second stage, only after referral by the pediatricians. Other services—such as specialty consultations (except pulmonology, cardiology, and allergy), laboratory and imaging tests, procedures, and surgeries—are referred to the Unified Health System (SUS), as this clinic is a partner of SUS.

Although there is no territorial delimitation, most of our patient population comes from the Itanhangá neighborhood, in the West Zone of Rio de Janeiro. This region is marked by contrasting types of housing: some located in gated communities and others distributed across six communities

(most of Rio das Pedras, Tijuquinha, Recanto da Barra da Tijuca, Morro do Banco, Vila da Paz, Sítio Pai João, Muzema, and Pedra do Itanhangá, also known as "Cloro"). According to the 2022 IBGE census, Muzema and Rio das Pedras are among the nine most populous communities in Rio de Janeiro. Rio das Pedras has 55,653 inhabitants, making it the second most populous community in the city and the second in the country in number of households, while Muzema has 12,982 inhabitants[17]. The Social Progress Index for this region is 65.2, ranking 71st among neighborhoods in the city of Rio de Janeiro, according to IBGE[18].

Although the variables used in this study are generally self-explanatory, some require further detail: the variable race/color is self-reported or reported by the mother. The reason for the first consultation was transcribed exactly as recorded in the medical chart, which explains the existence of a category labeled "Suspected Autism/ASD" and another labeled "ASD follow-up." This latter category is used when the caregiver states that the child/adolescent has ASD, which may or may not be accompanied by requests for medication, treatment, and/or documentation.

Some variables were adapted from the caregiver's wording as written in the chart: the variable "does not look" was transcribed as "does not maintain eye contact"; and the variable "speech-related concerns" was adapted from descriptions such as "does not speak," "difficulty speaking," "does not speak properly," "speech problem," "delayed speech," "speaks little," "not developing speech," or "incorrect speech." Similarly, for the variable "clinical complaint," we included specific or nonspecific clinical issues related to medical conditions or syndromes such as fever, vomiting, or skin changes, as well as complaints only reported by the mother/family in the context of a clinical condition, such as "won't eat," "eats poorly," "eats very little."

The variable "unspecified or different behavior" refers to situations in which the mother/family expressed concern without specifying the behavior, using expressions such as "strange behavior," "different behavior," or "behavior different from other children," among others. It is therefore important to note that the reason for the consultation was an unspecified behavior, as defined by this variable.

The date of ASD diagnosis refers to the date on which the diagnosis was confirmed; thus, preliminary diagnostic impressions of ASD suspicion were not considered, as these refer to moments when the patient was still under investigation and/or observation in our outpatient clinic. "Time in follow-up at the outpatient clinic" was defined as the interval between the date of the last appointment and the date of the first appointment.

The diagnosis of ASD is made through anamnesis (with detailed but not exclusive focus on developmental history), behavioral observation, screening tests such as the M-CHAT R/F and/or the Childhood Autism Rating Scale (CARS), in its Portuguese translation. In addition, DSM-5 diagnostic criteria are applied, and complementary tests are performed depending on the clinical presentation. It is important to emphasize that this is an interdisciplinary process that requires monitoring the child's progress through guidance and treatment. For this reason, pediatricians, the child psychiatrist, the pediatric neurologist, and the developmental pediatrician in our outpatient clinic are all involved in the diagnostic process, according to the needs and singularities of each child/adolescent and their family.

Quantitative variables were described using mean, standard deviation, median, and minimum and maximum limits (in parentheses). Categorical variables were presented as observed frequency/frequency of available data in the medical record (n/N), and percentage. The results were analyzed using SPSS software, version 21. The study was submitted to the Ethics Committee and approved under CAAE number 81133724.5.0000.5239.

RESULTS:

The study population corresponds to 8% of the children and adolescents seen at the Itanhangá clinic during the study period. Of the 295 medical records of children and adolescents seen during the study period with a diagnosis of ASD, 4 were excluded due to insufficient information. Thus, the final sample consisted of 291 medical records of children and adolescents. The mean age was 82.5 ± 43.9 months (21–206) (Table 2), with 79.7% (232/291) being children and 20.3% (59/291) adolescents (Table 1). In 96.5% (281/291) of the cases, maternal educational level reached incomplete primary school (Table 2). A total of 70.2% (204/291) were Brown/Black, and 72.2% (210/291) were male (Table 1).

Regarding gestational history, 8.1% (20/248) were small for gestational age (SGA), 15.2% (37/243) were premature, and 2.4% (6/250) had documented neonatal asphyxia and/or Apgar score below 7 at the 5th minute (Table 1). In 10.7% (29/270) of cases, mothers were smokers and/or used alcohol and/or illicit drugs during pregnancy.

Table 3 shows the description of signs and symptoms as reported by mothers during the first consultation. In some cases in which the reason for consultation was "agitation or hyperactivity" or "aggressive behavior," additional symptoms were noted, such as two cases of absent social interaction combined with aggressive behavior in the former, and agitation in the latter. Among cases categorized as "does not maintain eye contact," associated symptoms included agitation with continuous crying. In only three cases categorized as "clinical complaints" we observed, in addition to symptoms related to clinical diseases/syndromes, feeding-related concerns reported as part of maternal worry ("eats poorly," "eats very little," "does not eat").

The most frequent concerns leading to the consultation were those related to behavior (aggressive/agitation/hyperactive/unspecified), totaling 10.4% (30/289). The age

Table 1. Sociodemographic characteristics of the studied population – categorical variables.

Categorical variables of the study	n/N*	Percentage (%)
Sex		
Feminine	81/291	27.8
Masculine	210/291	72.2
FAge Range		
Children	232/291	79.7
Teenagers	59/291	20.3
Color/race		
Browns	195/291	67.1
Black people	9/291	3.1
white	87/291	29.8
Maternal education		
Illiterate	7/291	2.5
Incomplete primary education	274/291	94.1
Complete fundamentals	7/291	2.4
Incomplete secondary education	3/291	1.0
Gestational History		
Small for gestational age	20/248	8.1
Maternal Hypertension	69/270	25.6
Maternal Diabetes	21/242	8.7
HIV	3/275	1.1
Neonatal Asphyxia	6/250	2.4
Prematurity	37/243	15.2
Smoking and/or alcohol and/or illicit drug use	29/270	10.7
Suspected diagnosis		
Caregiver/family	135/166	81.3
Daycare/school	51/83	61.4
Preliminary diagnosis		
Yes	97/288	33.7
não	191/288	66.3

n – value referring to the number of cases in which that specific variable was answered
N – value referring to the total number of medical records in which the variable was available, regardless of response, excluding those in which the information was not provided
HIV – Human Immunodeficiency Virus

at symptom onset, as reported by caregivers, was 29.5 ± 21.9 months (Table 2). In 33.7% (97/288), caregivers arrived at our outpatient clinic with a prior diagnosis. The age at diagnosis (for those with and without a prior diagnosis) was 63.2 ± 39.7 months (Table 2). Even when considering only those with a prior diagnosis, the age at diagnosis was still 79.9 ± 43.6 months (Table 2).

DISCUSSION:

In this population living in conditions of social vulnerability, caregivers/family members were the primary individuals to perceive the first signs of ASD in children (62.5%), with a significant delay between the initial perception of symptoms and the age at diagnosis.

Table 2. Sociodemographic characteristics of the population served – continuous variables.

Continuous variables of the study	n/N	Mean ± standard deviation median	Minimum limit - maximum
Age (months)	216/216	83±47.375	21-345
Gestational History			
Gestational age	243/271	38.4 ± 2.139	29 -42
Apgar 1 min	249/291	8.3 ± 9.09	3 -10
Apgar 5º min	250/291	9.0 ± 0.696	6 - 10
Onset of symptoms (months)	181/291	29.5 ± 21.924	3-144
Age at diagnosis	277/291	63.2 ± 39.751	13 - 196
Age at diagnosis (in those with a previous diagnosis)	89/291	79.9 ± 43.669	17-196

Table 3. Reasons reported by the caregiver for the first outpatient visit.

Reason for consultation reported by the person in charge.	n/N	Porcentagem (%)
Suspected ASD/autism	46/286	16
He claims to have ASD/autism.	40/286	14
Clinical complaint/routine	95/286	33.2
Agitation/hyperactivity, with or without other symptoms.	16/286	5.6
Aggressive behavior, with or without other symptoms.	4/286	1.3
Does not maintain eye contact and other symptoms	3/286	1
It does not interact.	1/286	0.4
Complaints related to speech	21/286	7.3
Unspecified or different behavior	10/286	3.5
Developmental delay	7/286	2.4
Seizures	3/286	1.0
Learning difficulties	2/286	0.7
Referred by the daycare/school	11/286	3.8
Referred by another hospital	1/286	0.3
Neurological monitoring	17/286	5.9
Referral to a child psychiatrist.	4/286	1.4
Request for psychological/speech therapy/occupational therapy treatment	3/286	1.0
Suspected mental deficiency	1/286	0.3
Changes in sleep	1/286	0.3

Greater parental involvement in the recognition of ASD signs has consistently been reported in the literature. Most caregivers identify early signs before the age of 3, with 50% doing so by age 2. Similar findings are described both in international and national studies19,20,21. Therefore, it is essential that physicians value caregivers' concerns; however, this requires knowledge of ASD signs and symptoms, as well as familiarity with existing screening tools.

Clinical complaints were the most frequent reason for seeking consultation. This finding contrasts with the fact that 81.3% of families/caregivers already suspected the diagnosis, and 66.3% did not have a confirmed diagnosis upon arrival at our clinic. Even so, they did not mention the suspicion as the reason for the visit. Ribeiro et al. (2017), in a study on barriers to early autism diagnosis in Brazil, reported that 56.3% of mothers had negative experiences with physicians

and felt discouraged from voicing their concerns again22. This is noted as an important barrier to early diagnosis. In another Brazilian study, 42.8% of caregivers had negative experiences with pediatricians21.

The time elapsed between caregivers' first perception of symptoms and the age at diagnosis not only reinforces the previous discussion but also highlights the importance of ASD screening. Ribeiro et al., in 2017, observed an approximate 3-year gap between these two milestones22. In our study, we found a very similar interval of approximately 34 months. Thus, over a 7-year period between our study and the one cited, the time between the appearance of first symptoms and diagnosis remains around 3 years, despite differences in study methods. This prolonged time to diagnosis is also a significant source of physical and psychological burden for families, especially mothers16.

Other barriers mentioned in the literature include confusion and frustration with the diagnostic process, high levels of stigma in some communities, lack of information provided to parents, and the failure of healthcare professionals to value caregivers' concerns23. These findings further emphasize the importance of developmental surveillance during consultations, even when the visit is routine or prompted by unrelated clinical issues23. Moreover, a good clinical history is built through empathetic communication with the family, increasing the likelihood that they will share their fears and difficulties regarding their child, ultimately aiding in the diagnostic process and helping families navigate the challenges of accessing treatment.

The results of the present study show that most of these children/adolescents did not have a gestational history with risk factors for their development. Thus, pediatricians should perform frequent ASD screening with periodic re-evaluations, because caregivers may not verbalize their concerns, and there may be no identifiable risk factors for developmental delays. It is also important to highlight that completing the child health booklet is an important screening tool, and that both tools create opportunities for guidance and counseling regarding development, benefiting all children who present delays or deviations, even when ASD is not the diagnosis.

Our results show that caregivers most frequently bring behavior-related concerns as the reason for the consultation, possibly because such issues are socially more disruptive. Social interaction does not appear as a major concern, but speech does, in second place. In another Brazilian study, speech was the most frequent complaint, in addition to repetitive behaviors21. As in the study by Siqueira et al. (2022), referenced earlier, feeding-related issues—as described in the DSM-5 criteria—did not appear as the main reason for the first visit. These differences demonstrate an important factor in constructing the diagnosis of ASD: the heterogeneity of its signs and symptoms. The various clinical syndromes involved in ASD presentations highlight the need to view the condition as a continuum of different manifestations rather than fixed, uniform symptoms. Factors such as sex, genetic variability, socio-environmental and cultural influences, and both medical and neuropsychiatric comorbidities influence different clinical presentations24.

Preschools/schools also played an important role (61.4%) in raising diagnostic suspicion, as reported in another Brazilian study21. This reinforces the importance of schools in referring children for medical evaluation. The relevance of teachers in detecting developmental disorders is highlighted in the work of Hosokawa et al. (2020), which used data from the Millennium Cohort, a nationally representative cohort in the United Kingdom. Among children diagnosed with ASD in primary school, teachers had identified social developmental differences at age 5 in 45% of cases. Among those diagnosed in secondary school, teachers had already detected social developmental issues at age 5 in 50% of cases, even when caregivers had not yet identified differences in their children. These findings had greater predictive value among families with low income25.

Our results underscore the importance of conducting more Brazilian studies that examine issues specific to our reality regarding ASD diagnosis. However, Brazilian literature on the topic is scarce16, and international authors highlight that studies with white populations are far more frequent (64.8%), with a large gap compared to studies involving underrepresented populations such as Latino/Hispanic, Black, and Asian groups (6.4% to 9.4%)26.

With the rising prevalence of ASD and the shortage of child neurologists and psychiatrists in Brazil, ASD diagnosis conducted by pediatricians is becoming increasingly common27. There is little discussion of the topic in medical school and pediatric residency programs, making pediatric practice highly challenging28. Recently, the Brazilian Society of Child Neurology published a *Standardization Proposal for the Diagnosis, Investigation and Treatment of Autism Spectrum Disorder*, providing guidance for managing these cases27. However, it is necessary for medical school and pediatric residency programs to include Developmental Pediatrics as an essential and permanent topic in the curriculum, as well as to establish a formal specialization in developmental pediatrics. Lifespan development—including neuropsychological and mental health aspects—is complex, and requires in-depth training to improve understanding not only of ASD but also of the many clinical syndromes affecting children and adolescents, especially in the post-COVID-19 era29,30.

Moreover, it is necessary to revitalize medical education with themes such as empathy and building trust between families and pediatricians. This enables families not only to freely express their concerns but also to feel that the pediatrician is genuinely attentive to their issues and acting as a partner in the diagnostic process.

This study has limitations, such as its retrospective design and missing information in some medical records. However, it also has strengths, including the characterization of

ASD diagnosis in a population from an area of significant social vulnerability—data that are needed and rarely found in Brazilian literature, as discussed above—as well as the systematic search in both electronic and physical records.

REFERENCES

1. American Psychiatric Association. Manual diagnóstico e estatístico de transtornos Mentais : DSM-5. 5ª. Edição. Tradução: Maria Ines Corrêa Nascimento et al. Porto Alegre: Artmed, 2014.
2. Maenner MJ, Shaw KA, Baio J, Washington A, Patrick M, DiRienzo M et al. Prevalence of Autism Spectrum Disorder among aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016. MMWR Surveill Summ. [internet] 2020 [citado em 2024 set 30] Mar 27; 69(4): 1–12. Disponível em: https://pmc.ncbi.nlm.nih.gov/articles/PMC7119644/pdf/ss6904a1.pdf
3. Shaw KA, Bilder DA, McArthur D, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ [internet] 2023[citado em 2024 set 30];72(No. SS-1):1–15. Disponível em: http://dx.doi.org/10.15585/mmwr.ss7201a1.
4. Baron-Cohen S, Allen J, Gillberg C. Can autism be detected at 18 months? the needle, the haystack, and the CHAT. Br J Psychiatry. 1992;161:839-843.
5. Johnson CP, Myers SM; American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics. [internet] 2007[citado em 2024 set 30];120(5): 1183–1215 [citado em 2024 out 4]. Disponível em: https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of.
6. Ministério da Saúde (BR). **Caderneta da Criança**: Menina – Passaporte da cidadania. 3ª edição. Brasília: Ministério da Saúde, 2005.
7. Ministério da Saúde (BR). **Caderneta da Criança**: Menina – Passaporte da cidadania. 3ª edição. Brasília: Ministério da Saúde, 2021.
8. Ministério da Saúde (BR). **Caderneta da Criança**: Menino – Passaporte da cidadania. 3ª edição. Brasília: Ministério da Saúde, 2021.
9. Ministério da Saúde (BR). Diretrizes de atenção à reabilitação da pessoa com transtorno do espectro autista [internet]. Brasília: Ministério da Saúde [internet] 2014. [citado em 2024 out 08]. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_atencao_reabilitacao_pessoa_autismo.pdf
10. Sociedade Brasileira de Pediatria. Departamento Científico de Pediatria do Desenvolvimento e Comportamento. Triagem precoce para Autismo/ Transtorno do Espectro Autista . Rio de Janeiro: SBP [internet]; 2017 [citado em 2024 out 04]. Disponível em: https://www.sbp.com.br/fileadmin/user_upload/2017/04/19464b-DocCient-Autismo.pdf
11. Losapio MF, Ponde MP. Tradução para o português da escala M-CHAT para rastreamento precoce de autismo. Rev Psiquiatr Rio Gd Sul. 2008;30(3):221-9.
12. Sociedade Brasileira de Pediatria. Departamento Científico de Pediatria do Desenvolvimento e Comportamento. Transtorno do Espectro do Autismo. Rio de Janeiro: SBP [internet] ; 2024 [citado em 2024 out 18]. Disponível em: https://www.sbp.com.br/fileadmin/user_upload/Ped._Desenvolvimento_-_21775b-MO_-_Transtorno_do_Espectro_do_Autismo.pdf
13. Sociedade Brasileira de Pediatria. Departamento Científico de Pediatria do Desenvolvimento e Comportamento. Triagem Precoce para Autismo Modified Checklist for Autism in Toddlers – M-CHAT-R/F. Rio de Janeiro: SBP [internet]; 2024 [citado em 2024 out 16]. Disponível em: https://www.sbp.com.br/fileadmin/user_upload/24331c-MO_Triagem_Perecoce_para_Autismo.pdf
14. Reichow B, Hume K, Barton EE, Boyd BA. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews [internet] 2018, Issue 5. Art. No.: CD009260. [citado em 2024 oct 09]. Disponível em: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009260.pub3/full
15. Ministério da Saúde (BR). TEA: saiba o que é o Transtorno do Espectro Autista e como o SUS tem dado assistência a pacientes e familiares. Ministério da Saúde [internet]. Atualizado em 03/11/2022. [citado em 2024 out 22]. Disponível em: https://www.gov.br/saude/pt-br/assuntos/noticias/2022/abril/tea-saiba-o-que-e-o-transtorno-do-espectro-autista-e-como-o-sus-tem-dado-assistencia-a-pacientes-e-familiares
16. Sukiennik R, Marchezan J, Scornavacca F. Challenges on Diagnoses and Assessments Related to Autism Spectrum Disorder in Brazil: A Systematic Review. Front. Neurol.[internet] 2022; 12:598073. [citado em 2024 dez 2]. Disponível em: https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2021.598073/full
17. Grinberg F & Araújo C. Veja quais são as maiores favelas do Rio pelo Censo 2022. O Globo [internet].2024 nov 8. [citado em 2024 dez 2]. Disponível em: https://oglobo.globo.com/rio/noticia/2024/11/08/veja-quais-sao-as-maiores-favelas-do-rio-pelo-censo-2022.ghtml
18. Instituto Pereira Passos. Rio Prefeitura. Índice de Progresso Social do Rio de Janeiro 2022. Prefeitura da Cidade do Rio de Janeiro. [internet]. [citado em 2024 dez 9]. Disponível em : https://ips-rio-pcrj.hub.arcgis.com/pages/ipsbairros
19. Coonrod EE, Stone WL. Early concerns of parents of children with autistic and nonautistic disorders. Infants Young Child. 2004;17(3):258–268
20. Locke J, Ibanez LV, Posner E, Frederick L,Carpentier P, Stone WL. Parent Perceptions About Communicating With Providers Regarding Early Autism Concerns. Pediatrics [internet] 2020; 145 (Supplement_1): S72–S80. [citado em 2024 nov 04]. Disponível em https://doi.org/10.1542/peds.2019-1895J
21. Siqueira BNL, Prazeres ACLF, Maia AMLR. Os desafios do Transtorno do Espectro Autista: da suspeita ao diagnóstico. Resid Pediatr. [internet] 2022;12(2). [citado em 2024 nov 03]. Disponível em https://cdn.publisher.gn1.link/residenciapediatrica.com.br/pdf/v12n2aop339.pdf
22. Ribeiro SH, de Paula CS, Bordini D, Mari JJ, Caetano S. Barriers to early identification of autism in Brazil. RBP [internet] 2017 [citado em 2024 out 23]; 39:352-354. Disponível em: https://www.scielo.br/j/rbp/a/RFkqgsBhSvWDxtDjKWcmKZj/?lang=en
23. Walsh C, Lydon S, O'Dowd E, O'Connor P. Barriers to Healthcare for Persons with Autism: A Systematic Review of the Literature and Development of A Taxonomy. Dev. Neurorehabilit. [internet] 2020, 1–18. [citado em 2024 nov 04]. Disponível em: https://doi.org/10.1080/17518423.2020.1716868
24. Masi A, DeMayo MM, Glozier N, Guastella AJ. An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options. Neurosci Bull. [internet] 2017 Apr;33(2):183-193.[citado em 2024 nov 10]. Disponível em: https://pmc.ncbi.nlm.nih.gov/articles/PMC5360849/pdf/12264_2017_Article_100.pdf
25. Hosozawa M, Sacker A, Mandy W, Midouhas E, Flouri E, Cable N. Determinants of an autism spectrum disorder diagnosis in childhood and adolescence: Evidence from the UK Millennium Cohort Study. Autism [internet] 2020 Aug;24(6):1557-1565 [citado em 2024 nov 05]. Disponível em: https://pmc.ncbi.nlm.nih.gov/articles/PMC7645602/pdf/10.1177_1362361320913671.pdf
26. Steinbrenner, J. R., McIntyre, N., Rentschler, L. F., Pearson, J. N., Luelmo, P., Jaramillo, M. E., Boyd, B. A., Wong, C., Nowell, S. W., Odom, S. L., & Hume, K. A. Patterns in reporting and participant inclusion related to race and ethnicity in autism intervention literature: Data from a large-scale systematic review of evidence-based practices. Autism [internet] 2022, 26(8), 2026-2040.[citado em 2024 nov30]. Disponível em: https://doi.org/10.1177/13623613211072593

27. Montenegro MA, van der Linden Junior H, Casella EB, Gadia C, Celeri EHRV, Sampaio LPB. Proposta de Padronização Para o Diagnóstico, Investigação e Tratamento do Transtorno do Espectro Autista. São Paulo: SBNI [internet] 2021 Jul; [acesso em 2024 nov 01]. Disponível em: https://sbni.org.br/proposta-de-padronizacaopara-o-diagnostico-investigacao-e-tratamento-do-transtorno-doespectro-autista/

28. Souza NE, Raslan IR, Inácio Filho AR, Oliveira BCRCL. O papel do pediatra no reconhecimento precoce dos sinais e sintomas do transtorno do espectro autista: revisão de literatura. Resid Pediatr [internet]. 2021;11(3):1-6 . [citado em 2024 nov 15]. Disponível em : https://cdn.publisher.gn1.link/residenciapediatrica.com.br/pdf/v11n3aop234.pdf

29. Davico C, Marcotulli D, Abbracciavento G, Anfosso T, Apicella M, Averna R, Bazzoni M, Calderoni D, Cammisa L, Carta A, Carucci S, Cozzi G, Di Santo F, Fazzi E, Lux C, Narducci C, Nobili L, Onida I, Pisano T, Raucci U, Sforzi I, Siri L, Sotgiu S, Tavano S, Terrinoni A, Uccella S, Vicari S, Zanus C, Vitiello B; Italian Covid-Child and Adolescent Psychiatric Emergencies Study Group. COVID-19 Pandemic School Disruptions and Acute Mental Health in Children and Adolescents. JAMA Netw Open [internet]. 2024 Aug 1;7(8):e2425829. [citado em 2024 nov 20] Disponível em: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2821950

30. Fortes CPDD, Vieira F, Machado LC. Análise comparativa entre a saúde mental de responsáveis por pessoas com TEA e por crianças sem TEA na pandemia de COVID-19. Resid Pediatr.[internet] 2021;11(1):1-24. [citado em 2024 nov 6]. Disponível em: https://cdn.publisher.gn1.link/residenciapediatrica.com.br/pdf/rp100821a06.pdf.