Living with Autism Spectrum Disorder: Diagnosis, therapeutic approaches, and impact on families

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ABSTRACT

During the last few decades, there has been a significant increase in the number of cases of Autism Spectrum Disorder (ASD). Children diagnosed with autism have unique needs and patterns of behavior, including difficulties in communication, limitations in social interaction, disinterest in social activities, and often an unstable temperament. This demands understanding and continuous dedication from those who live with them. The objective of this study is to investigate the essential elements related to diagnosis, treatment and the impact of ASD on family dynamics. This research is descriptive, with qualitative analysis and data collected through a questionnaire answered by 11 family members. The results indicate that many families initially deny the symptoms presented by their children, which delays the search for medical help. In addition, the acceptance of the diagnosis is often a challenging process, affecting various feelings and the family structure. However, the knowledge gained about the disorder allows families to engage in therapies that contribute to the child's development. In this sense, there is a movement in which families seek support and society mobilizes to improve the quality of life of people with ASD.

Keywords: Autism, Diagnosis, Treatment, Family support.

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INTRODUCTION

Autism spectrum disorder (ASD) is a complex neurological condition that affects an individual's social, behavioral, and communication development. According to Lopez-Pison, et al. (2014, p. 403), autism or ASD, is a behavioral syndrome that compromises motor and psychoneurological development, hindering the child's cognition, language and social interaction. Its cause and origin is still unknown, and it is therefore considered a syndrome that involves neurological, social and genetic factors of the child (Volkmar; McPartland, 2014).

It is estimated that 70 million people in the world live with this condition, 2 million of them in Brazil. Over the years, the classification of autism has changed. Today, Autism Spectrum Disorder, or ASD, encompasses a series of levels, mild, moderate or severe, being more frequent in boys (Brasil, 2023).

The child with autism has very unique needs and behavior patterns, capable of being recognized by those with whom they live, such as parents, families, among others. The difficulty in communication, the lack of social interaction and lack of interest in social activities are noticeable, in addition to an unstable temperament that requires understanding and constant dedication from those who are in his life. Therefore, it is a condition that causes changes in the family routine due to the need to monitor the child's development. In this sense, this article aims to investigate the essential elements related to diagnosis, treatment and the impact of ASD on family dynamics.

METHODOLOGY

The research is descriptive and according to Matias-Pereira (2010, p.72) this type of research describes the characteristics of a certain population or phenomenon, or the establishment of relationships between the populations. As for the approach to the problem, the research is qualitative and does not require the use of statistical methods or techniques, with the natural environment being the direct source for data collection (Matias-Pereira, 2010, p. 71). The data were collected through a questionnaire with eight open questions, applied to 11 mothers of autistic children from November 3 to December 3, 2023 at the service center for people with disabilities in the city of Buritis - Ro, with the purpose of knowing the impacts that caring for an autistic child can cause in the family routine. Thus, this study addresses three dimensions: the diagnosis, treatment, and family impact of ASD.

THEORETICAL FRAMEWORK

DEFINITION, CLASSIFICATION AND DIAGNOSIS OF THE PERSON WITH AUTISM SPECTRUM DISORDER

According to the National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder, autism is considered to be a person with "persistent and clinically significant impairment of social communication and interaction, manifested by marked impairment of verbal and non-verbal communication used for social interaction; absence of social reciprocity; failure to develop and maintain relationships appropriate to their level of development" (Brasil, 2012).

Eugene Bleuler used the expression "autism" for the first time in 1911, to define the indifference to reality and the difficulty or impossibility of communicating in some schizophrenic patients (Assumpção Jr. & Kuczynski, 2018, p. 21).

Around 1943, Kanner, observing eleven children, concluded that they had a unique disease that was characterized by extreme isolation, repetitive behavior, stereotypies and echolalia. Kanner immediately used the term Bleuler for a diagnosis of schizophrenia, but noted that the disease encompassed a set of signs of its own, intending it to be a new disease.

The following year, Hans Aspeger (1944), after observing the behavior of 4 boys, realized that they had a recognizable pathology. They exhibited a vital disturbance in expressive functions and marked behaviors, and did not present differentiated physical characteristics. Asperger (1944) noted that the disorder caused great difficulties in social interaction, causing social problems to hinder the child's development process. He also realized that simple social problems were less severe, and was compensated by a high degree of originality of thought.

Asperger proposed in his research a definition of the disorder that he called autism mental disorder. It is marked by severe loss in social interaction. Conversa used the report of certain clinical cases, indicating the family history, physical and behavioral aspects, performance in intelligence tests, also highlighting the concern with the educational issue of these individuals (Sella; Ribeiro, 2018).

From 1981 onwards, the term Asperger's Syndrome was frequently used by Wing, and since then, many studies have focused on the discovery and knowledge of the criteria for diagnosing the syndrome. Its properties are related to qualitative changes in the area of reciprocal social interaction, in the development of restricted and repetitive patterns of behavior, activities and interests, as well as stereotyped behaviors and echolalic speech (ICD 10 F84).

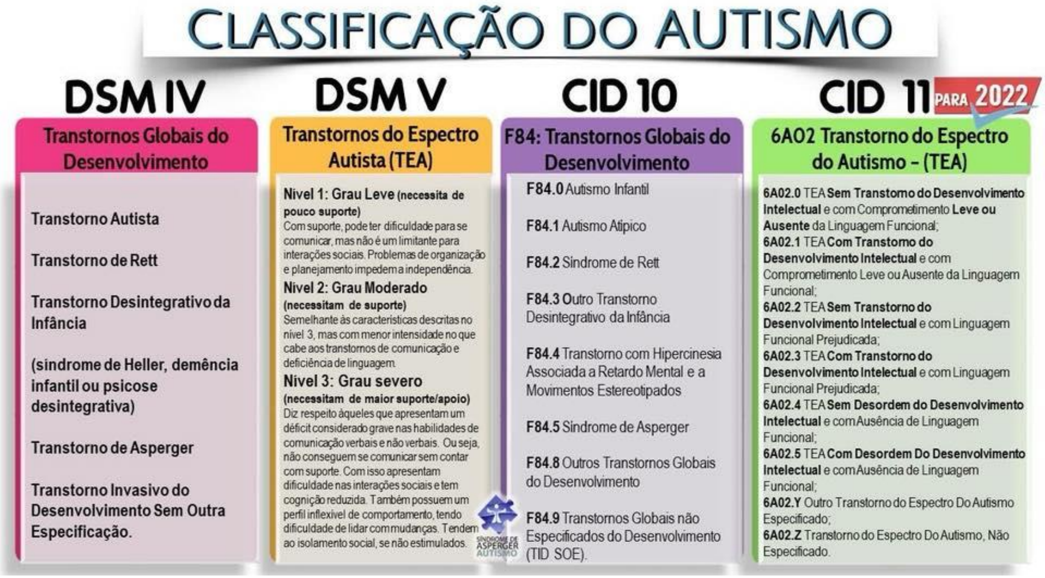
The World Health Organization – WHO presented the 11th revision of the ICD in June 2018, which was approved in May 2019. In the new document, ASD encompasses what was conceptualized as Pervasive Developmental Disorder in the ICD-10. According to the latest determinations of the Diagnostic Manual of Mental Disorders (DSM), ICD 11 gathered and unified all conditions with autism characteristics (Almeida, et al., 2020).

The International Statistical Classification of Diseases and Related Health Problems (ICD-11) is a broad, current, and important version of diseases, disorders, and health conditions. The new document is based on up-to-date scientific evidence and encompasses the progress of medical conditions. It is a document consulted worldwide because it sets standards for research, statistics or epidemiological situations.

It started operating in January 2022 and from the first day it started using the terminology Autism Spectrum Disorder to cover all diagnoses, which were previously classified in the ICD-10 as Pervasive Developmental Disorder (PDD). For example: childhood autism, atypical autism, Asperger's syndrome, childhood disintegrative disorder, hyperkinesia disorder associated with mental retardation and stereotyped movements [...] (WHO, 2018).

Chart 1 shows the association of these disorders by comparing the ICD-10 with the ICD-11.

Figure - 1 Classification of Autism



CLASSIFICAÇÃO DO AUTISMO

DSM IV	DSM V	CID 10	CID 11 PARA 2022
Transtornos Globais do Desenvolvimento	Transtornos do Espectro Autista (TEA)	F84: Transtornos Globais do Desenvolvimento	6A02 Transtorno do Espectro do Autismo - (TEA)
Transtorno Autista Transtorno de Rett Transtorno Desintegrativo da Infância (sindrome de Heller, demência infantil ou psicose desintegrativa) Transtorno de Asperger Transtorno Invasivo do Desenvolvimento Sem Outra Especificação.	**Nivel 1: Grau Leve (necessita de pouco suporte)** Com suporte, pode ter dificuldade para se comunicar, mas não é um limitante para interações sociais. Problemas de organização e planejamento impedem a independência. **Nivel 2: Grau Moderado (necessitam de suporte)** Semelhante às caracteristicas descritas no nivel 3, mas com menor intensidade no que cabe aos transtornos de comunicação e deficiência de linguagem. **Nivel 3: Grau severo (necessitam de maior suporte/apoio)** Diz respeito àqueles que apresentam um déficit considerado grave nas habilidades de comunicação verbais e não verbais. Ou seja, não conseguem se comunicar sem contar com suporte. Com isso apresentam dificuldade nas interações sociais e tem cognição reduzida. Também possuem um perfil inflexivel de comportamento, tendo dificuldade de lidar com mudanças. Tendem ao isolamento social, se não estimulados.	**F84.0** Autismo Infantil **F84.1** Autismo Atipico **F84.2** Sindrome de Rett **F84.3** Outro Transtorno Desintegrativo da Infância **F84.4** Transtorno com Hipercinesia Associada a Retardo Mental e a Movimentos Estereotipados **F84.5** Sindrome de Asperger **F84.8** Outros Transtornos Globais do Desenvolvimento **F84.9** Transtornos Globais não Especificados do Desenvolvimento (TID SOE).	**6A02.0** TEA **Sem Transtorno do Desenvolvimento Intelectual** e com Comprometimento **Leve ou Ausente** da Linguagem Funcional; **6A02.1** TEA **Com Transtorno do Desenvolvimento Intelectual** e com Comprometimento Leve ou Ausente da Linguagem Funcional; **6A02.2** TEA **Sem Transtorno do Desenvolvimento Intelectual** e com Linguagem Funcional Prejudicada; **6A02.3** TEA **Com Transtorno do Desenvolvimento Intelectual** e com Linguagem Funcional Prejudicada; **6A02.4** TEA **Sem Desordem do Desenvolvimento Intelectual** e com Ausência de Linguagem Funcional; **6A02.5** TEA **Com Desordem Do Desenvolvimento Intelectual** e com Ausência de Linguagem Funcional; **6A02.Y** Outro Transtorno do Espectro Do Autismo Especificado; **6A02.Z** Transtorno do Espectro Do Autismo, Não Especificado.

Source: Autimates Brasil (2018)

Autism Spectrum Disorder, code 6A02 in ICD-11, replaces ICD-10 code F84.0. Regarding the subdivisions, they are listed according to the existence or absence of Intellectual Disability and/or functional language impairment. Figure 1 shows this configuration.

According to Fernandes (2020, p.1), in ICD-11 - TEA (6A02) the following are listed:

6A02.0 – Autism Spectrum Disorder without Intellectual Developmental Disorder and with mild or no functional language impairment.

> **6A02.1**– Autism Spectrum Disorder with Autism Disorder Intellectual development and with mild or no impairment of the functional language. (Fernandes, 2020, p.1)

Intellectual development and functional language are included in the new subdivisions, namely:

6A02.2 – Autism Spectrum Disorder without Intellectual Developmental Disorder and with impaired functional language.

6A02.3 – Autism Spectrum Disorder with Intellectual Developmental Disorder and impaired functional language.

6A02.5 – Autism Spectrum Disorder with Intellectual Developmental Disorder and absence of functional language.

6A02.Y – Other specified Autism Spectrum Disorder.

6A02. Z – Autism Spectrum Disorder, unspecified.

It is important to highlight that the code "6A02.4 – Autism Spectrum Disorder without intellectual disability (ID) and with absence of functional language" was left out of the final version of the ICD-11. (Fernandes, 2020, p.1).

CHARACTERISTICS, DIAGNOSES AND NEEDS OF PEOPLE WITH AUTISM SPECTRUM DISORDER - ASD

The diagnosis of ASD is based on criteria established by the DSM-5, which include persistent deficits in communication and social interaction, as well as restricted and repetitive patterns of behavior, interests, or activities. The diagnostic process is multidisciplinary, involving mental health professionals, pediatricians, psychologists, and occupational therapists. Observation of the individual's behavior, along with specific tests and interviews with parents or guardians, is crucial for an accurate diagnosis.

The ASD subdivisions in ICD 11 enable a greater understanding of the functionality of the individual with ASD, an advance when we think about the need to carry out early and assertive diagnoses and interventions in Autism Spectrum Disorder (Almeida, et al. 2020).

The different degrees of autism allow us to reflect on the characterization of the disorder since there are different degrees of awareness and cognition of the person with ASD, which are determined by the care given to them throughout their growth. Considering that there are different individuals with different needs and growth, disability becomes much more complex, as it introduces diversity into an already unequal social issue that, in essence, needs greater understanding (Moreira, 2020).

Regardless of the level of autism, whether mild, medium, or severe, they all have difficulties in social interactions and need support for their autonomy (Costa et al., 2023).

According to Schechter & Grether (2008), cases of autism have grown worldwide, as a consequence of the earlier identification of these cases. In Brazil, despite the advances related to the early identification and diagnosis of autism, many children still remain without a diagnosis or with wrong diagnoses for a long time, a fact that is increasingly common in Brazilian schools where practically all of them have children with the characteristics, but without the autism diagnosis report, which is established based on a list of behavioral criteria (Silva; Mulick, 2009).

Figure 2- Criteria for diagnosing ASD

Critérios para Diagnóstico do Autismo

Para serem classificados como autistas, as pessoas devem manifestar pelo menos seis dos sintomas descritos no DSM antes dos três anos de idade.

PREJUÍZOS NA INTERAÇÃO SOCIAL (Pelos menos 2 das características a seguir):

- Prejuízo significativo no uso de comportamentos não verbais, como contato visual direto, expressão facial, postura corporal e gestos de interação social.
- Incapacidade de estabelecer relações com seus pares, de acordo com seu nível de desenvolvimento.
- Falta de um desejo espontâneo de compartilhar situações agradáveis, interesses ou conquistas pessoais.
- Falta de reciprocidade social ou emocional.

PREJUÍZOS DA COMUNICAÇÃO (Pelo menos 1 das características a seguir):

- Atraso ou ausência do desenvolvimento da linguagem falada, bem como modos alternativos de comunicação, como gestos.
- Déficit significativo para iniciar e/ou manter uma conversa com outros (em pessoas com fala adequada).
- Uso da linguagem idiossincrático ou estereotipado e repetitivo.
- Ausência de brincadeiras apropriadas de imitação social ou de "faz de conta".

INTERESSES, ATIVIDADES E PADRÕES REPETITIVOS, LIMITADOS E ESTEREOTIPADOS DE COMPORTAMENTOS Pelo menos 1 das características a seguir):

- Preocupação com um ou diversos interesses estereotipados e limitados, anormais em foco ou em intensidade.
- Aderência inflexível a rotinas ou rituais disfuncionais.
- Movimentos motores repetitivos e estereotipados, como abanar as mãos e balançar o corpo.
- Preocupação persistente com uma parte especifica de um objeto.

SÍNDROME DE ASPERGER AUTISMO

O Desenvolvimento do Autismo - Thomas L. Whitman

Source: Asperger - ASD (2015).

According to the Diagnostic and Statistical Manual of Mental Disorders - DSM-V (2014), the diagnosis of Autism Spectrum Disorder (ASD) has to consider three criteria, observing their particularities. It is common for children with autism to often present very high behavioral difficulties such as: "hyperactivity, difficulty in providing and/or maintaining attention, hyperselective attention and impulsivity, as well as aggressive, self-destructive, disturbing and destructive behaviors" (Silva; Mulick, 2009, p.3).

Orrú (2010, p.3) when listing the characteristics that most highlight the individual with Asperger's Syndrome cites:

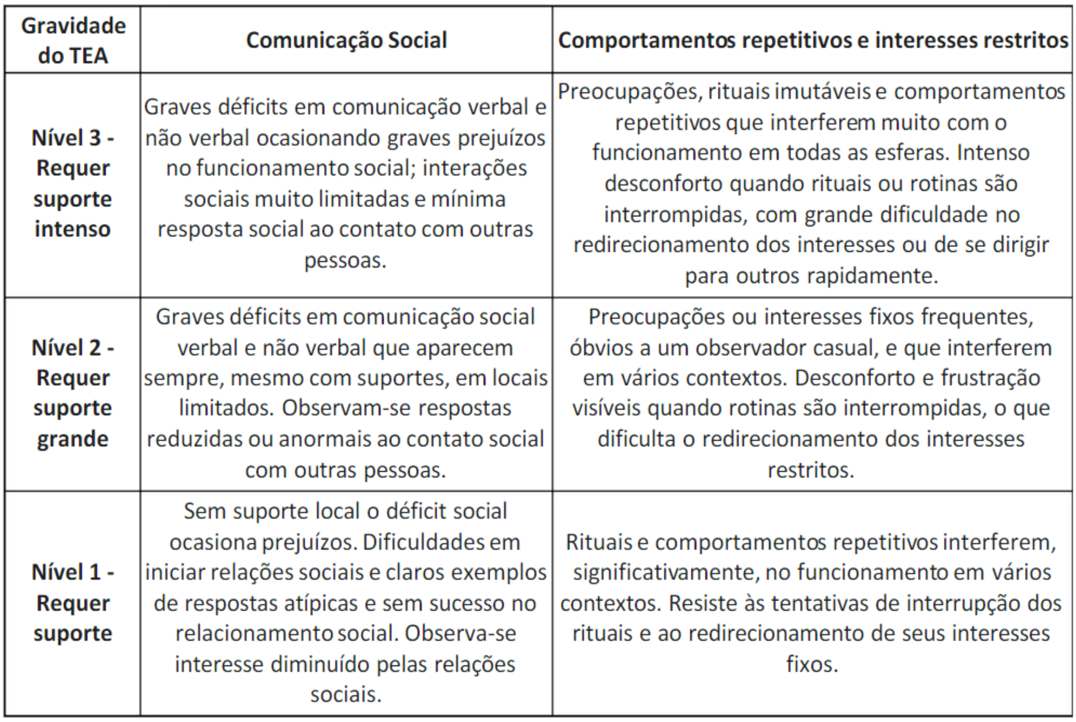
- ✓ Appearance of symptoms - Hardly recognized before 3 years of age, in general the diagnosis occurs around 5 or 6 years of age and often with suspicion of giftedness;
- ✓ Motor skills - Normal motor development, but with some psychomotor disabilities, giving an aspect of clumsiness;
- ✓ Perceptual processes - Perception always directed to the whole/excellent associated memory;
- ✓ Eye contact - Shallow, but always present;
- ✓ Social development – Communicates socially spontaneously, but memorizes the rules of the social game;
- ✓ Game patterns/interests - Explores objects properly from the beginning of development. It has specific, restricted and unusual interests;

- ✓ Speech/language - There is usually no delay in the appearance of speech, which is usually pedantic and unusual for age. There is grammatically structured speech, but with pragmatic changes
- ✓ Development of reading and writing - Spontaneous development at an early age (hyperlexia) in most cases. They are people who require constant care and attention, as they cannot express themselves or communicate with the world around them.

The severity levels of the different degrees of ASD are characterized in figure 3. Analyzing it, it is evident that at the three levels, whether the lowest or the highest, the person with autism needs support to have a comfortable life. Thus, the legal mechanism created to recognize and guarantee the rights of persons with disabilities, such as the United Nations Convention, the Statute of Persons with Disabilities and new provisions of the Civil Code of 2002, were important initiatives to guarantee the dignity and the fight against the historical discrimination of these people. People with ASD need to be met in their needs and society needs to see and respect them in their singularities. To this end, the government must have instruments that can guarantee their rights (Orrú, 2010, p.3).

The National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder, Law No. 12,764 of December 27, 2012, determines that "the person with autism spectrum disorder is considered a person with a disability, for all legal purposes" (Brasil, 2012).

Figure 3 - ASD severity levels (DSM; APA, 2013)



Gravidade do TEA	Comunicação Social	Comportamentos repetitivos e interesses restritos
Nível 3 - Requer suporte intenso	Graves déficits em comunicação verbal e não verbal ocasionando graves prejuízos no funcionamento social; interações sociais muito limitadas e mínima resposta social ao contato com outras pessoas.	Preocupações, rituais imutáveis e comportamentos repetitivos que interferem muito com o funcionamento em todas as esferas. Intenso desconforto quando rituais ou rotinas são interrompidas, com grande dificuldade no redirecionamento dos interesses ou de se dirigir para outros rapidamente.
Nível 2 - Requer suporte grande	Graves déficits em comunicação social verbal e não verbal que aparecem sempre, mesmo com suportes, em locais limitados. Observam-se respostas reduzidas ou anormais ao contato social com outras pessoas.	Preocupações ou interesses fixos frequentes, óbvios a um observador casual, e que interferem em vários contextos. Desconforto e frustração visíveis quando rotinas são interrompidas, o que dificulta o redirecionamento dos interesses restritos.
Nível 1 - Requer suporte	Sem suporte local o déficit social ocasiona prejuízos. Dificuldades em iniciar relações sociais e claros exemplos de respostas atípicas e sem sucesso no relacionamento social. Observa-se interesse diminuído pelas relações sociais.	Rituais e comportamentos repetitivos interferem, significativamente, no funcionamento em vários contextos. Resiste às tentativas de interrupção dos rituais e ao redirecionamento de seus interesses fixos.

Source: Sella, Ribeiro (2018).

In this sense, the person with ASD must be attended to and according to the criteria of the person with disabilities so that they can overcome their limitations and gain autonomy.

Until the middle of the last century, people with ASD were inmates in their homes or psychiatric institutions. With the development of medicine, several possibilities for integrating these individuals into society have emerged. New psychotherapeutic methods favor the coexistence of autistic people with their family and the environment that surrounds them. Therapeutic approaches for ASD are diverse and depend on the individual needs of each person. Behavioral therapies, such as Applied Behavior Analysis (ABA), are widely used to promote social skills, language, and reduce problem behaviors. In addition, occupational and speech therapies can be implemented to improve functionality and communication. In this bias, professional support and family care is important for the integration of the person with ASD. It is important to note that there is no cure for ASD, but early and continuous interventions have shown positive results in improving the quality of life and developing the individual's skills.

IMPACT ON FAMILY DYNAMICS WITH ASD

The family that has a child with a disability goes through many emotional stages that begin with denial, then with the acceptance of the diagnosis and finally treatment. Many families resist the diagnosis and delay treatment, thus making it difficult to recover from symptoms.

Creating actions for the integration and inclusion of people with ASD should be an attribution not only of the family, but also of society and the State, as already established in the Inclusion Law. However, the responsibility of parents is essential and determinant for the success of inclusion. The autistic individual needs to immediately count on the help and support of his family. This support is indispensable and fundamental for the development of children with ASD.

When parents are aware of their role and present in the execution of activities that favor the growth of their children, they seek help and fight for the inclusion process. In this way, they seek in the laws the legal support that attests to their rights and gives them the conditions to continue helping the autistic person more efficiently.

In this context, Luiz Felipe Gomide (2020) from Jusbrasil lists some benefits that autistic families can use to offer them better living conditions:

- ✓ According to the Brazilian Law of Inclusion (LBI), access to school for children and adolescents cannot be denied under any circumstances, whether in the public or private network.
- ✓ In case of need, the student with ASD may have access to a school support professional, such as a support teacher, to assist in the learning process in the classroom. No additional amount can be charged in the monthly fees due to the Inconvenience.

- ✓ The health insurance law provides for mandatory coverage for the diseases listed in ICD 10, which includes all types of developmental disorders (Gomide, 2023).

It is essential that the family knows its rights so that it can claim them. In this sense, the National Civil Aviation Agency - ANAC, created Resolution No. 280/2013 that grants discounts on air tickets.

On the procedures related to the accessibility of passengers in need of special assistance to air transport, determining that companies are required to guarantee an 80% discount on air tickets for companions of passengers with disabilities who cannot travel alone (ANAC, 2023).

Actions like this is a thermometer that society is mobilizing and recognizing the difficulties faced by people with ASD and their families.

LEGAL RIGHTS AND GUARANTEES OF THE PERSON WITH ASD

The Federal Constitution of 1988 already deals with people with disabilities without limiting the distinction of species of this genus due to the programmatic character of these constitutional provisions (Moraes et al., 2022).

Article 227 of the Federal Constitution of 1988 states that it is the duty of the family, society and the State to ensure that children and adolescents with disabilities can fully exercise their fundamental rights (Sella; Ribeiro, 2018).

Article 4 of Law No. 12,764/12 establishes that a person with ASD will not be subjected to inhuman or degrading treatment, will not be deprived of their liberty or family life, and will not suffer discrimination based on disability. It is observed that the law guarantees that autistic people are treated with respect and dignity (Costa et al., 2023).

The Ministry of Health (2015) also reinforces that people with Autism Spectrum Disorder (ASD) have rights, according to the Federal Constitution of 1988 and other specific laws and regulations, to provide comprehensive care.

Another advance in the sense of guaranteeing the right of people with ASD came through Law No. 13,977 of January 9, 2020, which instituted the Identification Card for Persons with Autism Spectrum Disorder (CIPTEA), and provides other measures. Popularly known as the Romeo Mion Law, this Law clarifies that "the public and private establishments referred to in Law No. 10,048, of November 8, 2000, may use the puzzle tape, a worldwide symbol of awareness of autism spectrum disorder, to identify the priority due to people with autism spectrum disorder." (Brazil, 2020)

Figure 4 - Preferential care for Autistic People

Source:Autismolegal.com

As established in Law 14.626/23, autistic people now have "the right to priority care for people with autism spectrum disorder or reduced mobility and for blood donors.

Placing autistic people on the list of preferential care is recognizing that the person with ASD faces uncomfortable situations, arising from the environment, which can cause an uncomfortable reaction for themselves and their families.

RESULTS

Fear, insecurity, guilt are feelings that affect those who are about to hear news for which they are not prepared. In the case of a child patient, parents are much more apprehensive since their children are often placed in their hopes and dreams. Receiving a diagnosis of a chronic disease is to break plans, it is to lead the family to walk an unknown and tortuous path. Having a child with a behavior different from the concept of normal causes changes in family dynamics.

Thus, when asking the parents when they noticed a difference in their children's behavior and the age at which they took them to the doctor, they answered as shown in Table 1.

Table 1. Difference between the child's behavior and the age of the first consultation

1. Have you noticed anything in the child's behavior? How old was when you took it to the doctor?	
E1	*Yes, the way to play - 4 years old*
E2	*Yes, 10 years old*
E3	*Yes. Physical behavior and language. 8 years*
E4	*Inadequate body posture - 5 years old*
E5	*Yes - 11 years old*
E6	*Not interacting with people - 8 years*
E7	*Yes. He liked to play with pencils. 5 years I took to the speech therapist*
E8	*Yes, instability in socialization - 5 years*
E9	*Since she was 6 months old, she has been accompanied by a neuropediatrician*
E10	*Yes, in their behavior. They are Gemini. It's been 4 years*
E11	*Yes, in the difficulty of interacting - 12 years old*

It is observed that most parents took their children to high school late for evaluation and diagnosis. It is common for parents to procrastinate this decision for fear of an unfavorable diagnosis, so they usually justify that it is the child's way, that he will later improve. Another reason to make the first appointment difficult is to get a place with a specialist. Although there is an increase in the supply of these services, we still have a deficit of specialized professionals.

Table 2. Impact of the diagnosis disclosure for the family

2. The impact of the disclosure of the autism diagnosis for the family?	
E1	*It was very bad. I felt unable to cope with the situation*
E2	*The revelation was horrible, we didn't want to accept it*
E3	*Impact of low self-esteem, panic, and disability*
E4	*Set of diverse sensations and feelings, such as frustration, guilt and others*
E5	*It was hard, but everyone understood*
E6	*It was difficult because we didn't know anything about it, so we had a lot of work*
E7	*It was devastating because we didn't have much guidance on the subject*
E8	*It was well accepted*
E9	*No one is prepared to receive this news*
E10	*low self-esteem, the two have autism. 1 mild and one moderate.*
E11	*In the clinic with the professionals. Guide to the group of experts*

It is observed that all families felt stunned by the diagnosis. For them it was difficult to know that their children had a disease that for most was unknown, that they had no information and did not know how to deal with. They experienced a mix of emotions such as guilt, frustration, insecurity, low self-esteem and the attitude of denial. Facing reality and preparing for the diagnosis requires strength and a change in the family. Knowing that their child is different gives mothers a feeling of protection, and fear of rejection. However, despite the whirlwind of feelings and emotions, all the family members interviewed answered that they received the diagnosis in the office, by the specialized team that advised them to start treatment. The care and respect of the professionals with the children was clear. Support at this time is essential because families feel fragile and lost, not knowing what direction to take to help their children, as shown in table 3.

Table 3. Receiving the child's diagnosis and treatment guidance

3. How was your diagnosis given? Did you receive any guidance?	
E1	*It was the experts in the area. They advised him to do the treatment.*
E2	*In the clinic for therapeutic follow-up as soon as possible*
E3	*In the office. Yes, we would have to start treatment*
E4	*In the doctor's office - look for a specialist*
E5	*Therapy together with psychologist, speech therapist, physical educator, etc*
E6	*By the medical report. He guided us a lot but you have to study all the concepts*
E7	*I had a lot of support and guidance on how to proceed with the treatment*
E8	*Inside the consultation. Be accompanied by a team of professionals*
E9	*Late, with 9 years old, but he has since 1 year PC report*
E10	*By specialists through diagnosis. Group therapy.*
E11	*In a clinic with specialized professionals*

It is evident that for many families ASD is something unknown and for others, they had already heard about it, however, it was something distant, since it did not exist in the family, it did not arouse much interest. Having this revelation causes a change in attitude and the family starts to seek information and knowledge to be able to better understand and serve their children. Gradually, the feeling of denial disappears and the search for treatment begins to occupy the center of family concerns, as shown in tables 4 and 5.

Table 4. Knowledge about ASD

4. Have you ever heard about autism?	
E1	*yes, sometimes*
E2	*yes*
E3	*Yes, but knowing that your child has it is something of great emotional impact*
E4	*Yes, but I didn't imagine having one in my family*
E5	*Yes*
E6	*No. We were very laymen in this, we had to study a lot and go deeper*
E7	*Yes, but I didn't imagine it could happen to my son*
E8	*yes*
E9	*Sim, on phonodiólogo*
E10	*Yes I heard but it's hard to deal with reality*
E11	*Yes, many times but we don't want to believe that our son has*

By analyzing the place where the treatment is carried out, it was found that there is a variety of institutions, offering the therapies that the child with ASD needs and that the families need to take him so that the treatment is satisfactory and develops the child. This variety of therapies requires availability from families, so to provide this service, families need time, hence, some benefits have already been achieved in this regard, such as the reduction of work hours. See table 5.

Table 5. Place where the treatment is carried out

5. Where do you do the treatment?	
E1	*In a clinic with the specialists*
E2	*With a specialized team*
E3	*Unified Health System, with a specialized team*
E4	*In a clinic with specialized professionals*
E5	*APAE, Health Center*
E6	*At the Health Center and at the CAPS*
E7	*CAPS, APC, Health Center*
E8	*With neurologist, psychopedagogue, APAE*
E9	*Private clinic, rosy house in PVM*
E10	*In a clinic, with a specialized team*
E11	*In a clinic, with a specialized team*

Meeting the needs of the child with ASD requires a joint family effort, so the family relationship is important. When asking how this relationship occurred in their families, the respondents claimed that they had a good relationship, but children with ASD did not like to interact. There were no testimonies regarding the relationship with other family members, such as uncles, cousins, among others. They also did not indicate exclusion of the family with ASD. However, the fact that the child does not like to interact, by itself, already moves away from movements that are not comfortable for him, characterizing an exclusion. It is necessary for families to take a close look so that this isolation is less and less. See table 6.

Table 6. Relationship with family

6. How is the child's relationship with the family (parents, siblings, uncles, cousins, etc.)	
E1	*Doesn't like to interact*
E2	*Doesn't like to interact*
E3	*Doesn't like to interact*
E4	*Relationship is good*
E5	*Have a good relationship*
E6	*It's very good, very respectful*
E7	*Relationship is good*
E8	*Doesn't like to interact*
E9	*No Response*
E10	*Doesn't like to interact*
E11	*Doesn't like to interact*

Regarding the care of children, the participants answered that they follow the treatment indicated by the doctor and other normal care pertinent to a child.

Table 7. Routine of children with ASD and family care

7. What is the childcare routine like?	
E1	*He has difficulty interacting. Normal care*
E2	*He doesn't like to interact. Necessary care indicated by the doctor*
E3	*He likes to be isolated. Structured routine for his well-being*
E4	*He doesn't even interact with his family. Normal routine with special attention.*
E5	*The routine is very busy because there are several therapies*
E6	*Very good. Of great respect. Take it to therapies and to school and speech therapy.*
E7	*Normal*
E8	*With attention recommended by the experts*
E9	*23h of care because he is 19 years old, does not speak, wears a diaper and cannot do anything without the help of another person.*
E10	*They like to be isolated*
E11	*They like to be isolated, they don't interact*

It is verified that the routine indicated for treatment has a schedule of visits to specialists such as speech therapist, neurologist, psychologist, going to school, among others. There are cases where ASD is more severe, and autistic people require care to perform basic activities, such as the E9 testimony. See Table 7.

Caring for a person with ASD is not a simple or one-off task, it is a constant dedication. Autistic people have unpredictable reactions and a particular way of living life, and it is up to everyone around them to contribute to making them feel as comfortable as possible.

Recognizing the particularities of individuals with ASD is to guarantee their rights already established by law. As studies advance in favor of knowledge about the diagnosis and treatment of ASD, society also advances in the implementation of inclusion actions and in the availability of resources and services that favor the well-being and quality of life of autistic people and their families or caregivers. In this bias, family members know their rights and use the benefits already conquered that contribute to a more dignified life for individuals with ASD.

Table 8. Knowledge about the benefits for people with ASD and family

8. There are several rights and benefits of autistic people and families, can you name any?	
E1	*Reduction of workload, school inclusion, priority attendance, and others.*
E2	*Yes, school inclusion, health care and others*
E3	*Identification card, school inclusion, priority service and others.*
E4	*Identification card, school inclusion, priority service and others.*
E5	*Yes, one of the LOAS benefits*
E6	*Assistant Professor and vacancies in the job market*
E7	*Reduction of workload, benefit of the federal government*
E8	*Right to benefits, classroom monitoring, among others.*
E9	*INSS aid, priority in queues, treatment by SUS, enrollment in schools*
E10	*School inclusion, treatment by the SUS, priority care, among others*
E11	*Treatment by SUS, cheaper transportation, school inclusion*

It was observed that from school inclusion, individual monitoring at school, financial help by the government, reduction of workload, free care by the SUS, priority in care, among others, were benefits achieved by autistic people and their families (Vasconcelos, 2023). It is evident that these achievements do not solve all the difficulties that autistic people and their families face in their daily lives, but it is already an advance in the recognition of the disorder.

CONCLUSION

The impact of ASD on families is significant and multifaceted. Family members face emotional, financial, and social challenges when dealing with the special needs of the member with ASD. Searching for appropriate therapies and treatments can be costly, in addition to the time and energy invested in providing support and care. However, the family impact is not exclusively negative. Many families find strength in unity, adopt resilience strategies and promote mutually supportive environments. Learning about ASD can bring family members closer together, create empathy, and raise awareness of the special needs, not only of individuals with ASD, but all family members.

ASD is a complex condition that requires understanding, support, and adequate resources to improve the quality of life of affected individuals. Early diagnosis, followed by personalized interventions and family support, plays a crucial role in the development and well-being of individuals with ASD. In this context, it is vital that society promotes inclusion, awareness and support for families, recognizing the abilities and potential of each person with ASD. The journey with ASD can be challenging, but with support and understanding, families can face and overcome these challenges, strengthening family bonds and the community as a whole.

REFERENCES

1. Almeida, M. S. C., Sousa Filho, L. F., Rabelo, P. M., & Santiago, B. M. (2020). Classificação internacional das doenças - 11ª revisão: Da concepção à implementação. *Revista de Saúde Pública, 54*, 104.

2. Agência Nacional de Aviação Civil (ANAC). (2023). Resolução nº 280, de 11 de julho de 2013. Dispõe sobre os procedimentos relativos à acessibilidade de passageiros com necessidade de assistência especial ao transporte aéreo e dá outras providências. Disponível em: <https://www.anac.gov.br/assuntos/legislacao/legislacao-1/resolucoes/resolucoes-2013/resolucao-no-280-de-11-07-2013>

3. Assumpção Junior, F. B., & Kuczynski, E. (2018). Autismo: Conceito e diagnóstico. In *Análise do comportamento aplicada ao transtorno do espectro autista*. Curitiba: Appris.

4. Brasil, Planalto. (1988). *Constituição da República Federativa do Brasil de 1988*. Disponível em: <https://www.planalto.gov.br/ccivil_03/constituicao/constituicao.htm>

5. Brasil. Justiça do Trabalho - TRT 14ª Região. (2023). Decisão garante jornada de trabalho reduzida para pais de autistas. Disponível em: <https://portal.trt14.jus.br/portal/noticias/decisao-garante-jornada-de-trabalho-reduzida-para-pais-de-autistas>

6. Brasil. Presidência da República. (2020). Lei nº 13.977, de 8 de janeiro de 2020. Institui a Carteira de Identificação da Pessoa com Transtorno do Espectro Autista e altera a Lei nº 12.764, de 27 de dezembro de 2012. Disponível em: <http://www.planalto.gov.br/ccivil_03/_ato2019-2022/2020/lei/L13977.htm>

7. Brasil. Presidência da República. (2000). Lei nº 10.048, de 8 de novembro de 2000. Dá prioridade de atendimento às pessoas que especifica e dá outras providências. Casa Civil. Disponível em: <https://www.planalto.gov.br/ccivil_03/leis/l10048.htm>

8. Brasil. Ministérios da Educação. (n.d.). Autismo. Disponível em: <http://portal.mec.gov.br/component/tags/tag/autismo>

9. Brasil, Planalto. (2012). Política nacional de proteção dos direitos da pessoa com transtorno do espectro autista. Lei nº 12.764 de 27 de dezembro de 2012. Disponível em: <https://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/l12764.htm>

10. Costa, C. de L., Barbosa, I. L., & Da Paz, H. M. da S. (2023). Os impactos advindos da vigência da lei n° 12.764/2012 para a conquista de direitos da pessoa com transtorno de espectro autista (TEA). Disponível em: <https://repositorio-api.animaeducacao.com.br/server/api/core/bitstreams/c6b12e58-3ce1-44be-8acf-d29c12b40b19/content>

11. De Moraes, T. A. P., Das Chagas, S. M. da F. L., Bispo, E. P. de F., Fachin, L. P., & Júnior, V. A. da S. (2022). O direito a políticas públicas de saúde de um paciente com transtorno do espectro autista e sua consequência nas relações familiares: Um relato de caso. *Brazilian Journal of Development, 8*(6), 42575–42594. https://doi.org/10.34117/bjdv8n6-006

12. Gomide, L. F. (2020). Nove direitos que os pais das pessoas portadoras do Transtorno do Espectro do Autismo (TEA) devem saber. Disponível em: <https://www.jusbrasil.com.br/artigos/9-direitos-que-os-pais-das-criancas-portadoras-do-transtorno-do-espectro-do-autismo-tea-precisam-saber/663023339>

13. Lopez-Pison, J., Garcia-Jimenez, M. C., Monge-Galindo, L., Lafuente-Hidalgo, M., Perez-Delgado, R., & Garcia-Oguiza, A. (2014). Our experience with the etiological diagnosis of global developmental delay and intellectual disability: 2006-2010. *Neurologia, 29*(7), 402-407.

14. Volkmar, F. R., & McPartland, J. C. (2014). From Kanner to DSM-5: Autism as an evolving diagnostic concept. *Annual Review of Clinical Psychology, 10*, 193-212.

15. Fernandes, F. R. (2020). Autismo e Realidade. TEA na CID-11: O que muda? Disponível em: <https://autismoerealidade.org.br/2022/01/14/tea-na-cid-11-o-que-muda/#:~:text=Na%20CID%2D11%2C%20o%20Transtorno,ou%20comprometimento%20da%20linguagem%20funcional>

16. Gil, A. C. (2008). *Métodos e técnicas de pesquisa social* (6ª ed.). Atlas.

17. Matias-Pereira, J. (2010). *Manual de metodologia da pesquisa científica* (2ª ed.). Atlas.

18. Moreira, J. V. dos S. (2020). *Capacidade civil da pessoa com transtorno do espectro autista sob a égide da lei nº 13.146/2015* (Monografia de graduação em Direito). Faculdade de Direito, Universidade Federal do Ceará, Fortaleza, CE.

19. Orrú, S. E. (2010). Síndrome de Asperger: Aspectos científicos e educacionais. *Revista Iberoamericana de Educación, 53*, 7-10. Disponível em: <file:///C:/Users/Educa%C3%A7%C3%A3o/Desktop/sindrome%20de%20asperger.pdf>

20. Organização Mundial de Saúde. (2022). Versão final da nova classificação internacional de doenças da OMS (CID-11) é publicada. Disponível em: <https://www.paho.org/pt/noticias/11-2-2022-versao-final-da-nova-classificacao-internacional-doencas-da-oms-cid-11-e>

21. Sella, A. C., & Ribeiro, D. M. (2018). *Análise do comportamento aplicada ao transtorno do espectro autista*. Appris Editora e Livraria Eireli-ME.

22. Schechter, R., & Grether, J. K. (2008). Continuing increases in autism reported to California's Developmental Services System: Mercury in retrograde. *Archives of General Psychiatry, 65*(1), 19-24.

23. Silva, M., & Mulick, J. A. (2009). Diagnosticando o transtorno autista: Aspectos fundamentais e considerações práticas. Disponível em: <https://www.scielo.br/j/pcp/a/RP6tV9RTtbLNF9fnqvrMVXk/?lang=pt#>

24. Wing, L. (1981). Asperger syndrome: A clinical account. *Psychological Medicine, 21*, 115-129.

25. Vasconcelos, A. (Mar 2023). Transtorno do Espectro do Autismo (TEA): Como garantir a cobertura no plano de saúde. Disponível em: <https://www.jusbrasil.com.br/artigos/transtorno-do-espectro-do-autismo-tea-como-garantir-a-cobertura-do-plano-de-saude/1799373133>