

Providing Speech-Language Service for Children and Adolescents with Autism-A 20 Years Experience in Brazil

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INTRODUCTION

Through the years, there have been changes in the concept and diagnostic criteria for autism, in the forms of care, in the teaching programs, in the assistance laws. And naturally, researches in the field has always added something more to this great “puzzle” called Autism Spectrum Disorder.

Over time, studies showed different variations within the picture and with that, in 1979, Wing introduced the term “autism continuum”, bringing a concept of autism as a spectrum and this term is widely used up to current days [1,2].

The increase in prevalence is notorious over time and even though it does not appear to be related to a specific geographic location, a variation of the incidence in different regions can be observed, and may be related to the expansion/change of the diagnostic criteria, availability of services and Autism Spectrum Disorder (**ASD**) Awareness [3].

After the publication of DSM III [4], in which the term childhood autism appeared for the first time, it was considered that its prevalence reached one in 10,000 or even 50,000 children. Currently, some studies show that one in every 68 children is included in the Centers for Disease Control and Prevention [5] and although it is a very important fact, mainly for public policies, there are few Brazilian studies reporting these data.

Among the few studies on prevalence in Brazil, the Autism Project of the Institute of Psychiatry at the Clinical Hospital of Universidad de São Paulo reports that in 2007 there was approximately one person with ASD for every 190 inhabitants [6]. Another study conducted in 2011 showed a prevalence of 1 to 360 cases [7].

[3] analyzed data available from other countries and noted that ASD does not appear to be more prevalent in any specific geographic location, socioeconomic level or ethnicity, and the average estimated incidence was 62 per 10,000.

With changes in diagnostic criteria, it is difficult to define a period in which a real notion of the influence of DSM-5 on changes in the incidence of ASD can be obtained. [8] suggests that prevalence estimates may be lower with the DSM-5 criteria than with the DSM-IV-TR based criteria. In Brazil, it can be assumed that, in studies published up to 2015, most of the subjects analyzed were diagnosed according to DSM-IV criteria [9].

In its last published version, DSM-5 [10] proposes to classify Autism Spectrum Disorder (**ASD**) as a replacement for that of Global Developmental Disorders, adopted in DSM-IV-TR [11]. Thus showing a variety of this set of conditions that are part of the spectrum and the controversies regarding the differential diagnosis between them.

Besides the Diagnostic and Statistical Manual of Mental Disorders (**DSM**) that presents the most recognized diagnostic criteria, one of the references in mental health in Brazil [12] and an important instrument for classification and diagnosis of ASDs is the International Classification of Diseases-ICD 10 [13], published by the World Health Organization (**WHO**).

In addition to the Diagnostic and Statistical Manual of Mental Disorders (**DSM**), Autism is included in the Pervasive Developmental Disorders (**PDD**), which is part of the Classification of Mental Disorders and Behavior, subdivided into eight categories: Childhood Autism; Atypical autism; Rett syndrome; other disintegrative disorders of childhood; Hyperkinesia disorder associated with mental retardation and stereotyped movements; Asperger's syndrome; Other global developmental disorders; and Global development disorders not specified [12,13].

[13] defines TID as a group of disorders characterized by qualitative changes in reciprocal social interactions, communication patterns and by a restricted, stereotyped and repetitive repertoire of interests and activities. These qualitative anomalies constitute an overall characteristic of the functioning of the subject, in all situations.

Even with advances in criteria, the diagnosis is clinical and is based on standardized diagnostic tools such as the Autism Diagnostic Observation Schedule-ADOS [14] or Autism Diagnostic Interview-Revised-ADI-R [15], which are considered gold standard in the diagnostic part and follow the criteria proposed by ICD 10 [13] and by DSM V [10].

According to the diagnostic criteria of DSM-5, it is possible to observe the first manifestations of autism before 36 months of age.

In Brazil, to assist in early diagnosis, a law was passed this year that made it mandatory for the Unified National Health System (**SUS**) to adopt a protocol or other instrument built with the purpose of facilitating the detection of risk for psychic development. It should be applied to all children in their first eighteen months of life.

There is a consensus in the literature showing that the earlier the necessary treatments are initiated, the better the prognosis. However, studies show that the diagnosis continues to occur late, on average at 5 years of age, and can reach up to 10 years [16-18].

[16] also reported that the age difference at the time of diagnosis varied according to geographic location, thus suggesting that community resources and public policies play an important role in early identification.

In a study conducted by [19], 62 sites were selected initially for people with ASD in the city of São Paulo (Brazil), but only 25 of them agreed to participate in the study, with eleven special/inclusive schools, five associations, four clinics, four institutions and one non-governmental organization (**NGO**).

If access to a research is already restricted, finding a place of care for the treatment of individuals with ASD is not an easy task, as well as often having a great financial burden.

Thus, many parents/guardians sought laws that could help them with regard to the treatment of their children and over the years laws have been created that determine the duty of the State to ensure integrated care in Health and Education to the person with Autism and the extension to the service within the scope of the Unified National Health System was instituted.

The announcement of the Protocol for the Diagnosis, Treatment and Referral of Patients with Autistic Spectrum Disorder - ASD [20] represented an improvement and an increase in the changes regarding the rights of people with ASD, especially after the ASD were included as a disability in 2012. This Protocol also defined that the treatment of patients will be based on the degree of intensity of the disorder: those with less intensity should be treated in the Specialized Rehabilitation Centers (**REC**) of Unified National Health System (**SUS**) and patients with a higher intensity of will be referred to the Psychosocial Care Centers (**CAPS**).

In 1986, the Educational Outpatient Clinic in Speech-Language Pathology (**SLP**) in Child Psychiatry was implemented in the Child and Adolescent Psychiatry Service (**SEPIA**) of the Psychiatry Institute of the Clinical Hospital-Universidade de São Paulo Medical School (HC-FMUSP). During several years this was the only SLP service in a psychiatric hospital in Brazil [21,22].

After this general overview, this chapter seeks to describe a specialized care service in Autism Spectrum Disorders in one of the largest cities in Brazil for the last 20 years (from 1997 to 2016).

[22] reports that in 1997, after a curricular restructuring, there was an opportunity to integrate teaching and research activities in one place, and this was what we now call the Autism Spectrum

Disorders Research Laboratory (LIFDEA) of the Communication Sciences and Disorders Program-Universidade de São Paulo Medical School (FMUSP).

This service uses the pragmatic approach and, in addition to prioritizing research and teaching, it also represents an important specialized care activity. About 90 patients are attended weekly by five undergraduate students, two undergraduate students, five master's students, one doctoral student, and two postdoctoral students.

Considering the volume of people being treated and caregivers, having a systematic record of therapeutic data is essential. As reported by [23], who consider that the registration of therapeutic processes is fundamental, so that individual experiences can be analyzed in a significant way, as well as to contribute to clinical practice.

[23] further emphasize that, when related to the ASD, it is extremely important that the experiences be systematized and described so that they can help other patients who present the same needs but who were not diagnosed or did not find specialized care.

Another important aspect of [24] is that, through data management, it may be possible to prove the efficacy of the therapy, regardless of its theoretical, behavioral, pragmatic or otherwise, thus contributing to clinical practice based in evidence.

When analyzing the last decades it is possible to observe changes also in the functioning of the services that offer care to children with ASD. In the speech-language pathology, the changes involve both the diagnostic and intervention criteria as well as the research methodology and the systematization of diagnostic process data [24].

Studies with data stored in a system prove the possibilities of research with large populations, which is not common in the subject literature [24]. In addition, the systematization of data facilitates long-term visualization, evidencing that a minimum national standard for the diagnosis of AED is necessary. As was found in Australia, where systematization of data helped ensure best practice, regardless of the type of environment in which the service was provided, and became consistent with the international a better practice guidelines for ASD diagnosis [25].

[26] describe that the use of computers in the clinical documentation and follow-up represents an innovative change and at the same time a challenge for professionals, teachers and health trainees.

[19] concluded that quality management in the treatment offered to individuals with ASD is of paramount importance, especially when related to speech-language pathology. The authors found that several sites still neglect the importance of the audiologist's performance in the treatment of autistic individuals.

Studies show that the absence or delay of the first words and phrases is one of the main reasons for the parents' apprehension of children with ASD [27], bringing with them family concerns

about language development. As a result, one of the first professionals to be sought is the SLP, emphasizing the importance of speech-language assessment and early identification of a possible risk for some disorder [28].

The treatment, regardless of the chosen theoretical-clinical perspective, should begin as soon as possible and be adapted to the specific needs of each child and family. Intervention in the first years of life has a significant impact on the functioning of many autistic children, and parental involvement as co-therapists in some intervention programs is key [29,30].

Analyzing some epidemiological data regarding the characterization of the population served by the LIFDEA, it is observed that, during the period between January of 1997 and December of 2016, 442 subjects were evaluated, of which 354 were male.

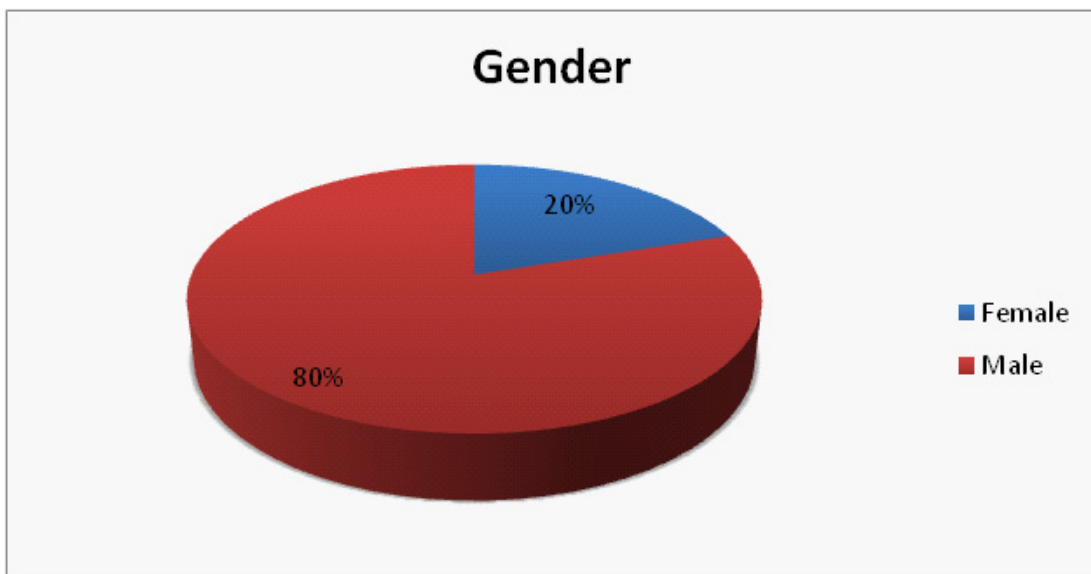


Chart 1: Gender Characterization of the sample.

This proportion corresponds to that observed in the literature that reports 5 male children, for every 1 female child diagnosed.

The age range of the beginning of the service varies from 1 to 20 years, and only 14% started the service before the age of 4 years. Patients who started treatment at the age of 4 to 8 years represented 59%, and 9.9% of the subjects started speech therapy beyond 11 years of age.

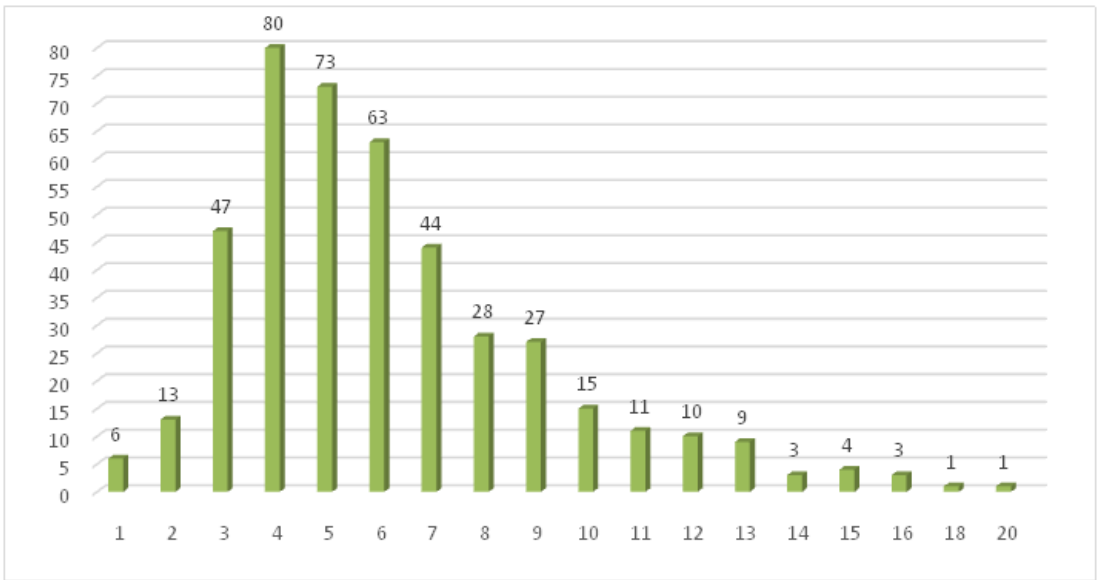


Chart 2: Treatment Starting Age Characterization of the sample.

During the analysis of the tabulated data, it was observed that the age of onset of therapy showed a decrease in the age group over the years, that is, in 1997 the mean age of onset was 6.1 years and in 2016 this age changed to be 3.5 years.

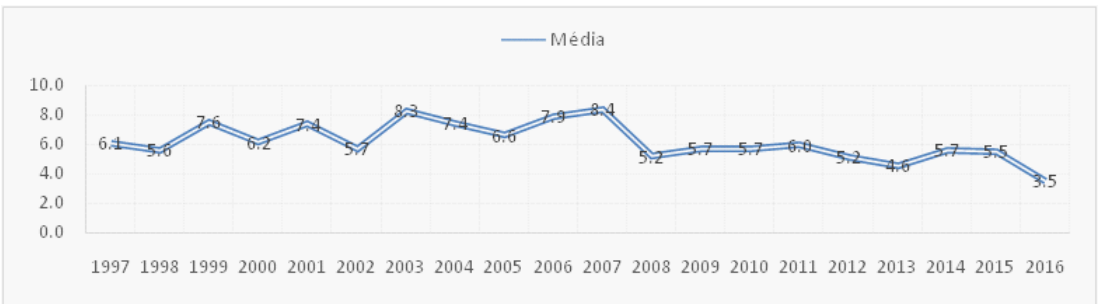


Chart 3: Average age of onset of assessment and speech-language therapy.

The median analysis was also performed for the comparison with the mean data due to some age variations in certain years, such as, for example, in the year 2007, in which a patient who underwent an initial evaluation at age 20 years. However, it was noted that in general, there is not much difference between the two analyzes and it was decided to maintain only the average.

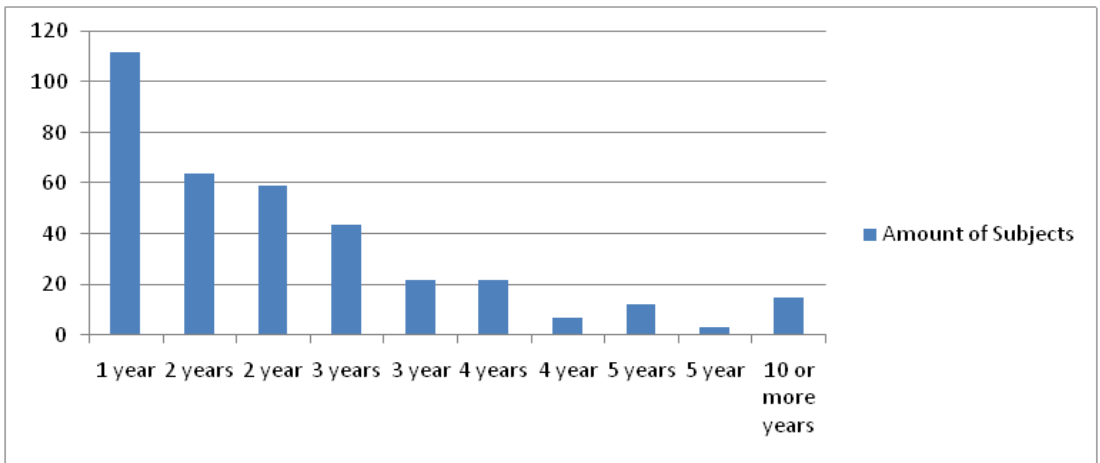


Chart 4: Length of time in service.

The mean time these children stay in care is 3 years, with a variation of less than 1 year of therapy at 15 years.

Most children who arrive for care (25%) have a year or less of speech therapy. Some of these patients only performed the evaluation and did not give continuity to the indicated treatment, even after returning the evaluation with the Continuity Treatment Conduct.

Analyzing the collected data, it is noticed that the main reason for the interruption of the treatment was the abandonment or withdrawal of the vacancy. The patients' representatives justify the interruption of the speech-language therapy to the question of distance from the place of residence to the place where this treatment is offered.

Considering that the city of São Paulo is the sixth most populous in the world and its size makes locomotion difficult, especially to those who depend on public transport, this can become a hindrance throughout the service period, thus necessitating the search a specialized care closer to your residence or even losing your place due to the number of absences.

Regarding the number of subjects who started the care, it is observed that the number of patients doubled when compared to the first years of analysis.

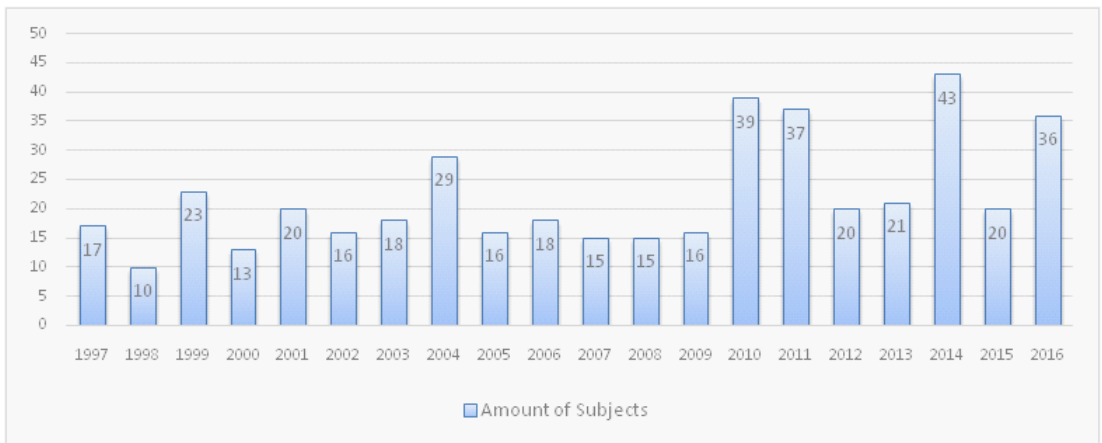


Chart 5: Number of subjects who began care over the years.

This significant increase may be related to an increase in ASD awareness and changes in diagnostic criteria, and it is increasingly evident the importance of systematizing and disseminating data such as these in order to increase and improve the availability of care services for individuals with autism.

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