

Brief Communication
Comunicação Breve

Danielle Azarias Defense-Netrval¹
Fernanda Dreux Miranda Fernandes¹

The provision of speech-language therapy in services destined to individuals with Autism Spectrum Disorder (ASD)

A oferta da terapia fonoaudiológica em locais de assistência a indivíduos com Transtornos do Espectro do Autista (TEA)

Keywords

Autism Spectrum Disorder
Speech-language Therapy
Assistance
Brazil
Therapy

Descritores

Transtorno do Espectro Autista
Fonoaudiologia
Assistência
Brasil
Terapia

ABSTRACT

The increased prevalence of autism spectrum disorder (ASD) worldwide has been a major public health concern; therefore, discussion about the services and therapies required has become important. This study aimed to characterize the provision of speech-language therapy services in the metropolitan area of Sao Paulo. To this end, a questionnaire with 23 questions was developed based on the Balanced Scorecard methodology. This questionnaire was applied to 854 individuals assisted in 25 ASD services. The results show that only 64% of the ASD services offer speech-language therapy and that the number of individuals assisted is below the expected. Therefore, there is a necessity for better management in the speech-language therapy services offered to the ASD population.

RESUMO

Os Transtornos do Espectro Autista (TEA) têm sido grande preocupação em saúde pública devido ao aumento de sua prevalência e isto traz à tona, a discussão sobre a assistência prestada assim como dos acompanhamentos terapêuticos necessários. Dentre estes acompanhamentos, se destaca a terapia fonoaudiológica. Este estudo buscou caracterizar a oferta desse serviço nos diversos locais de assistência a essa população no município de São Paulo e para isso, elaborou-se um questionário. Participaram do estudo 25 locais com um total de 854 indivíduos com TEA assistidos. Observou-se que apenas 64% dos locais oferecem o acompanhamento fonoaudiológico e que o número dos indivíduos com indicação para esse acompanhamento está aquém do esperado. Conclui-se que há necessidade de gerenciamento no serviço fonoaudiológico oferecido a esta população.

Correspondence address:

Danielle Azarias Defense-Netrval
Laboratório de Investigação
Fonoaudiológica dos Distúrbios do
Espectro Autístico
Departamento de Fisioterapia,
Fonoaudiologia e Terapia Ocupacional
Faculdade de Medicina
Universidade de São Paulo – USP
Rua Cipôtanea, 51, Cidade
Universitária, São Paulo (SP), Brazil,
CEP: 05360-000.
E-mail: danielledefense@gmail.com

Received: April 16, 2015

Accepted: December 14, 2015

Study carried out at Speech-Language in ASD Research Laboratory of the PT, OT and SLP&A, School of Medicine, Universidade de São Paulo – USP - São Paulo (SP), Brazil.

¹ Universidade de São Paulo – USP - São Paulo (SP), Brazil.

Financial support: CAPES.

Conflict of interests: nothing to declare.

INTRODUCTION

Literature has pointed out to an increase in the prevalence of Autism Spectrum Disorders (ASD) in the last years^(1,2), what places the issue as a main concern in public health. Apparently there are situations where this prevalence is lower because different diagnostic criteria are use or because the diagnosis is not determined at all.

In Brazil there are no comprehensive epidemiologic studies regarding this prevalence, just some estimates. A research conducted in 2010⁽³⁾ reported an estimative of about one million persons with ASD in Brazil. In 2012 it was suggested that there were 100 thousand persons with ASD just in the city of Sao Paulo and that most of them still didn't receive adequate diagnosis and/or treatment⁽⁴⁾.

Data available at the global network indicate that just seven of the 26 Brazilian states have any public policy towards persons with ASD. This situation highlights the difficulties in implementing the recommendations of the World Report on Disabilities due to geographic, demographic and social-economic diversity⁽⁵⁾ and to the fact that just recently ASD were included as a disability in the country⁽⁶⁾.

There is also a lack of data regarding the costs of assistance to children with ASD in Brazil. The financial and social impact of ASD in the families and in the public health system is also a factor that must be considered⁽⁷⁾. A non-governmental organization reports that the annual costs of treatment at a specialized institution in the city of Sao Paulo are of approximately R\$20,000.00 (that is, 23 times the Brazilian minimum wage)⁽⁷⁾.

The state of Sao Paulo is the richest of the country and has directed more attention to the public policies regarding persons with ASD. Probably it is also due to the mobilization of the families and advocacy initiatives that resulted on the Protection of Persons with ASD Law in 2008⁽⁸⁾ and on the City Attention Policy to Persons⁽⁹⁾ with ASD in 2011⁽¹⁰⁾.

ASD are a permanent disorder in which the persons need continuous multi-professional specialized treatment regardless of the severity of the symptoms^(6,11). The priority should be the adequate diagnosis as early as possible and immediate onset of therapeutic intervention, allowing a better prognosis.

Several prior studies stress the importance of speech-language therapy to persons with ASD⁽¹²⁾. Considering it, the purpose of this study was to assess the availability of language therapy and its limitations in various assistance centers to persons with ASD.

METHOD

This study and the consent form were approved by the institution's ethics committee with number 131/12.

To gather information about the assistance centers and the speech-language services available a questionnaire was developed. It was based on the proposal of a panel of performance indicators to the management of speech-language pathology (SLP) services in assistance centers for persons with ASD. These indicators were based on the four steps of the Balanced Scorecard⁽¹³⁾.

In Step 1, of processes identification, the researcher selected the variables: number of individuals with ASD,

availability of a professional SLP, referral to SLP, and number of speech-language therapy sessions per month. Regarding the results, the selected variables were: number of persons with ASD receiving speech-language therapy, presence of speech in the individuals with ASD, duration of the treatment and adherence to the treatment.

The researchers identified the variables that could characterize the population and the assistance centers. It was considered that this information could contribute to the understanding about what happens in the language intervention processes in these centers.

In Step 2 the indicators were determined. The process indicators were: number of subjects with just autism; number of subjects with high functioning autism; number of subjects with other conditions associated with autism; number of SLPs working in each center; number of subjects with ASD that were referred to language therapy; average number of language therapy sessions per month. The results indicators were: number of persons with ASD receiving language therapy; number of subjects with and without speech; average durations of the language therapy process; average length of the language therapy sessions; number of subjects that abandon treatment; number of subjects that return to the language therapy and number of subjects that drop out of the system.

The standardization of the data gathering procedures was determined in Step 3 through a questionnaire with questions focusing on the desired data. The final questionnaire has 23 objective questions where 13 were mandatory and 5 involved the characterization of the person that was being interviewed. The study used a network field system to identify the centers that were studied and the data gathering process was limited to just one individual interview per center. The inclusion criteria for the centers that participated in this study were: providing specialized services to persons with ASD and be located in the city limits of Sao Paulo. The initial sample comprised 62 centers but just 25 agreed to participate in the study. The data refer to a total of 854 individuals with ASD.

The obtained data were organized in spreadsheets and underwent statistical analysis aiming to identify significant clusters.

RESULTS

The 25 centers included in this study were geographically distributed within the city of Sao Paulo as follows: 11 in the south region, 4 in the central-west region, 4 in the east region and 6 in the north region.

The Chart 1 summarizes the data about the availability of language therapy and the average duration of the language treatment. According to this chart the school is the main center for attention to children with ASD, either special schools or regular schools with inclusion programs. Only 16 of the centers studied provide language therapy to their clients. The center with the larger SLP service is a non-governmental organization (NGO). The average number of SLP sessions per month is four and the durations of the treatment is undetermined. It is important to mention that the information about whether the language therapy sessions were individual- or group-sessions was not provided.

Another important issue is to consider that only 565 of the 854 subjects with ASD had been referred to language assessment and therapy; but the criteria to this procedure were not informed. Besides that, five of the nine centers without SLP services reported that they inform the families about the need for this intervention.

In Table 1 the data about the different diagnosis within the autism spectrum and different age-ranges are presented. It can be observed that that diagnosis of autism is the most frequent among the 854 individuals with ASD, followed by the association with other conditions (where mental deficits are the most frequent). Less than half of the considered individuals presented verbal communication. Although 565 subjects were referred to language therapy, just 428 of them were receiving it. The services are still mostly directed towards the children.

DISCUSSION

The geographic distribution of the specialized centers that comprised the sample of this study suggests an uneven distribution of the resources available to persons with ASD. The South is the wealthiest region of the city and concentrates most of the resources of São Paulo.

Almost half (40%) of the studied centers are schools, including special and regular schools with inclusion programs. It highlights the role of schools as a major reference point for receiving and managing this population. The larger proportion of schools in this sample also probably reflects the fact that the number of schools is much larger than the number of other institutions. Unfortunately many special schools do not have the proper permissions by the Ministry of Education and work

as treatment centers with educational assistance. There is much debate about the different roles of special schools and multidisciplinary treatment in specialized centers. Nevertheless, the inclusion of vulnerable children, such as the ones with ASD, in institutions that do not undergo the proper inspections by official authorities is an important indicator of the uneven quality of the services provided to persons with special needs. The alternative of providing “some service” to underserved populations may hide the lack of proper assistance⁽⁵⁾.

According to the data obtained, children from zero to 11 years and 11 months are better assisted, followed by the teenagers. Adults with ASD are still a vastly neglected group, either in what refers to places of treatment as to age-appropriate programs.

Speech-language services are provided in just 64% of the 25 centers that comprised the sample of this study. Therefore over 30% of the sample do not comply with state⁽¹¹⁾ and federal⁽¹⁴⁾ guidelines regarding treatment and education of persons with ASD which determine that the SLP should be part of the multidisciplinary team. It shows that SLP treatment is still neglected, despite the scientific evidence of this intervention to persons with ASD. The same could be concluded by the fact that the number of individuals referred to SLP services is below what should be expected considering that language is one of the major areas of impairments in ASD⁽¹²⁾.

The undetermined length of treatment may be associated to the very frequent individual variations regarding number and severity of symptoms and areas of impairment and to the fact that the treatment should be based in individualized therapeutic projects that improve the quality of life, autonomy, social inclusion and school and work adaptation.

Chart 1. Characterization of the centers

Types of centers	N	Length of treatment	Number of SLPs	Length of SLP treatment	Reference to SLP services	Number of SLP sessions per month/individual
School	10	From 24 months to undetermined	9	From 36 months to undetermined	161	from 4 to 16
Association	5	From 30 months to undetermined	8	Undetermined	276	from 3 to 20
Clinic	4	From 11 months to undetermined	1	From 36 months to undetermined	17	4
Institution	4	From 60 months to end	2	60 to 120 months	50	from 4 to 8
Clinical school	1	60 months	1	48 months	8	8
NGO	1	Undetermined	5	Undetermined	41	8
Total	25	-	26	-	565	111
Average		Undetermined	1	Undetermined	23	4 sessions

Table 1. Characteristics of Enrolled Subjects with ASD

	Diagnosis			Speakers	Subjects enrolled in SLP service
	A	HFA	AC		
Children	258	31	71	212	235
Teenagers	129	18	70	123	98
Adults	103	5	70	78	95
Total	490	54	211	413	428

Caption: A = Autism; HFA = High Functioning Autism; AC = Autism with other Conditions

Regarding the SLP intervention, it is relevant to point out that a previous study reported that intervention programs with once- or twice-a-week sessions didn't result in relevant differences but the frequency of the patients to the treatment did⁽¹⁵⁾.

CONCLUSION

It can be concluded that the provision of services to persons with ASD needs quality management, including SLP services. The results indicated that several specialized centers still neglect the role of this professional with persons with ASD. In some of them the families aren't informed about the need and alternatives for communication and language diagnosis and intervention or even have other professionals performing these functions.

The difficulties in obtaining information may be the reason for the lack of data about the needs of persons with ASD and the services available to them.

REFERENCES

1. Deutsch SI, Urbano MR. Preface. In: Deutsch SI, Urbano MR. Autism spectrum disorders: the role of genetics in diagnosis and treatment. Croácia: Intech; 2011 [citado em 2012 Out 10]. p. IX. Disponível em: <http://www.intechopen.com/books/autism-spectrum-disorders-the-role-of-genetics-in-diagnosis-and-treatment>. <http://dx.doi.org/10.5772/976>.
2. Bower BUS. autism rate continues to rise: prevalence estimate hits new high at 1 in 88 children. *Sci News*. 2012;181(9):14. <http://dx.doi.org/10.1002/scin.5591810915>.
3. Junior P, Ribeiro S. Pesquisa do CDC revela número alto de prevalência de autismo nos EUA em crianças de oito anos, além de grande aumento em relação a pesquisa anterior. *Revista Autismo: Informação Gerando Ação*. 2010;0(1):29. [citado em 2012 Out 10]. Disponível em: <http://www.revistaautismo.com.br/edic-o-0/numero-impressionante-uma-em-cada-110-criancas-tem-autismo>
4. Petição Pública Brasil. Abaixo-assinado pela aprovação projeto dos cinco Centros de Referência em Autismo em São Paulo. São Paulo: Petição Pública Brasil; 2012 [citado em 2012 Out 10]. Disponível em: <http://www.peticaopublica.com.br/PeticaoVer.aspx?pi=P2012N23097>
5. Fernandes FDM, Behlau M. Implications of the World Report on Disability for responding to communication disorders in Brazil. *Int J Speech-Language Pathol*. 2013;15(1):113-7. <http://dx.doi.org/10.3109/17549507.2012.731435>. Disponível em: <http://informahealthcare.com/doi/pdf/10.3109/17549507.2012.731435>. PMID:23215452.
6. Brasil. Lei nº 12.764, de 27 de dezembro de 2012. Institui a Política Nacional de Proteção dos Direitos da Pessoa com Transtorno do Espectro Autista. *Diário Oficial da União*; Brasília; 20 dez 2012 [citado em 2013 Jan 13]. Seção 1, p. 2. Disponível em: https://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/12764.htm
7. Autismo e Realidade [Internet]. Autismo e epidemiologia. São Paulo: Autismo e Realidade; 2015 [citado em 2015 Jan 13]. Disponível em: <http://autismoerealidade.org/informe-se/sobre-o-autismo/autismo-e-epidemiologia/>
8. São Paulo. Ministério Público do Estado. Ação civil pública: processos nº 053.00.027139-2 (1679/00) da 6ª Vara da Fazenda Pública do Ministério Público do Estado de São Paulo, de 28 de Dezembro de 2001. São Paulo: MPSP; 2011 [citado em 2011 Fev 20]. Disponível em: http://www.mpsp.mp.br/portal/page/portal/cao_civel/aa_ppdeficiencia/aa_ppd_autismo
9. São Paulo. Governo do Estado. Projeto de Lei nº 549/2008, de 19 de agosto de 2008. Institui a Lei de Proteção à Pessoa Portadora do Autismo. *Diário Oficial do Estado de São Paulo*; São Paulo; 19 ago 2008; 154, p. 42 [citado em 2011 Fev 20]. Disponível em: <http://www.al.sp.gov.br/propositura/?id=814871>
10. São Paulo. Câmara Municipal de São Paulo. Lei nº 15.409 de 11 de julho de 2011. Estabelece diretrizes a serem observadas na formulação da Política Municipal de Atendimento às Pessoas com Transtorno Invasivo do Desenvolvimento: autismo. *Diário Oficial da Cidade de São Paulo*; São Paulo; 12 jul 2011, 128, p. 1 [citado em 2012 Out 10]. Disponível em: ftp://ftp.saude.sp.gov.br/ftpssp/bibliote/informe_eletronico/2011/iels.jul.11/Iels129/M_LE-15409_110711.pdf
11. São Paulo. Secretaria da Saúde do Estado de São Paulo. Secretaria dos Direitos da Pessoa com Deficiência. Protocolo do Estado de São Paulo de Diagnóstico, Tratamento e Encaminhamento de Pacientes com Transtorno do Espectro Autista (TEA). São Paulo; 2013 [citado em 2013 Out 9]. Disponível em: <http://www.saude.sp.gov.br/ses/perfil/profissional-da-saude/homepage/destaques/direita/protocolo-do-estado-de-sao-paulo-de-diagnostico-tratamento-e-encaminhamento-de-pacientes-com-transtorno-do-espectro-autista-tea>
12. Fernandes FDM, Amato CAH, Molini-Avejonas DR. Language assessment in autism. In: Mohammad MR. A comprehensive book on autism spectrum disorders. Croácia: Intech; 2011 [citado em 2012 Out 10]. p. 3-22. Disponível em: <http://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/language-assessment-in-autism>
13. Kaplan RS, Norton DP. Using the balanced scorecard as a strategic management system. *Harvard Business Review*. Managing for the Long Term. 2007 [citado em 2011 Fev 2] 74(1):75-85. Disponível em: <http://sumup.cedu.upc.edu/reference-articles/using-bsc>
14. Brasil. Lei nº 10.216/2001, de 06 de abril de 2001. Dispõe sobre a proteção e os direitos das pessoas portadoras de transtornos mentais e redireciona o modelo assistencial em saúde mental. *Diário Oficial da União*; Brasília; 04 abr 2001, Seção 1, p. 2 [citado em 2014 Fev 9]. Disponível em: http://www.planalto.gov.br/ccivil_03/leis/leis_2001/110216.htm
15. Nascimento LA. Correlação entre frequência e evolução terapêutica em fonoaudiologia nos distúrbios do espectro autístico [dissertação]. São Paulo: Universidade de São Paulo, Faculdade de Medicina; 2013 [citado em 2014 Mar 12]. Disponível em: <http://www.teses.usp.br/teses/disponiveis/5/5162/tde-03012014-152105/fr.php>

Author contributions

DADN was responsible for data collection and literature review; FDMF was responsible for the organization, management and supervision of the study.