SEVEN publicações acadêmicas
EM PARCERIA COM:

AUTISM SPECTRUM DISORDER: DIFFICULTIES FOR EFFECTIVE INCLUSION

Marcelo Henrique de Souza[1], Giovanni José Vieira da Silva[2] and Lisienne de Morais Navarro G Silva[3]

ABSTRACT

This scientific work addresses the importance of including individuals with Autism Spectrum Disorder-ASD and seeks to understand the perceptions of guardians and/or caregivers of individuals with ASD on this topic. Autism Spectrum Disorder-ASD is part of a group of neurodevelopmental disorders, sharing core symptoms that include deficits in social skills, communication, and restricted and repetitive behaviors. The research proposes to give voice to the guardians and/or caregivers of individuals with ASD, so that they bring their perceptions about the obstacles faced when claiming the rights of the individual with ASD, and even after winning this claim, does the way this right is exercised meet the needs of the individual with ASD? The hypothesis raised is that the inclusion of these individuals in all dimensions - social, educational, labor market, digital, cultural, economic and political, is fundamental to create egalitarian environments and should involve public policies that foster awareness of all layers, but, unfortunately, it is believed that the law, as it is being applied, is still not meeting the needs of people with autism spectrum disorder - ASD. The objective is to identify how these conquered rights can be more effective in terms of supporting and promoting a more egalitarian society, what the support gaps are, and what the possible areas for improvement in the policies, practices, and services available are. The hypothesis raised is that promoting the social inclusion of individuals with ASD is essential to create an egalitarian environment, involving public policies that imply the awareness of all social strata. By addressing the perceptions of guardians and/or caregivers, this study aims to contribute to a deep understanding of the needs of individuals with ASD and identify opportunities to promote more effective inclusion in various social contexts. The research seeks to provide relevant insights that can foster more inclusive practices and policies that are sensitive to the needs of individuals with ASD.

Keywords: Autism Spectrum Disorder. Social inclusion. Perceptions of those responsible. Public policies.

INTRODUCTION

According to the American Psychological Association. APA), Autistic disorder is part of a group of neurodevelopmental disorders called Autism Spectrum Disorders (ASD), which include Pervasive Developmental Disorders (PDD) and Pervasive development disorders (PDD). These disorders share core symptoms, including deficits in social skills and communication (verbal and nonverbal) and the presence of restricted, repetitive, and stereotyped behaviors.

---

[1] Unip – SP
[2] Unip – SP
[3] Unip – SP

ASD encompasses and subsumes the disorders formerly known as autism, Asperger's disorder, and childhood disintegrative disorder, which are no longer considered distinct diagnoses in the DSM-5 and DSM-5-TR. Medical or genetic disorders associated with ASD, such as Rett syndrome, are identified as specifiers of the disorder.

Due to the characteristics of Autism Spectrum Disorder-ASD, which affect social and communication skills, the inclusion of a person with ASD in the family, at school, at work, or in society in general can be challenging. These difficulties often result in situations of prejudice, discrimination, rejection, and social withdrawal.

The inclusion and appreciation of individuals with ASD are fundamental issues that demand understanding and sensitivity on the part of society, especially those responsible and/or caregivers of these individuals. The term "inclusion" generally refers to the comprehensive effort to ensure that all people, regardless of their characteristics or circumstances, have equal access to opportunities and resources and full participation in society. According to Schilling and Miyashiro (2001), the inclusion would be: [...] to put in; to make it appear of; join(s) to; insert(se); introduce(se) [...]. Far beyond the meaning of a word, the research proposes to give voice to the guardians and/or caregivers of individuals with ASD, so that they can bring their perceptions about the obstacles faced when claiming the rights of the individual with ASD, and, after winning this claim, does the way this right is applied meet the needs of the individual with ASD?

The hypothesis raised is that the inclusion of these individuals in all dimensions - social, educational, labor market, digital, cultural, economic and political, is fundamental to create egalitarian environments and should involve public policies that foster awareness of all layers, but, unfortunately, it is believed that the law, as it is being applied, is still not meeting the needs of people with autism spectrum disorder - ASD.

In this context, this research seeks to understand the perceptions of guardians and/or caregivers about the inclusion of individuals with ASD. Giving voice to caregivers and/or caregivers in order to explore the difficulties faced in the search for effective inclusion, we seek to identify problem areas, support gaps, and possible areas for improvement in available policies, practices, and services.

OBJECTIVE

The general objective of this research is to investigate the perceptions of guardians and/or caregivers about the dimensions of inclusion of individuals with ASD.

Identify the difficulties that are faced in the inclusion process regardless of dimension and analyze the perceptions of the guardians and/or caregivers of the individual with ASD.

Accesses that promote interaction with other members of society for individuals with ASD help to stimulate their social skills, avoiding isolation. At the heart of the concept is the idea that skills can be developed through the interactions that occur during the social learning process. However, it is necessary to respect the particularities of each individual in this process. Individuals with typical development can offer, among other things, examples of interaction for autistic people, even if the social understanding of the latter is challenging. Interaction with other individuals is critical for growth, whether the individual is autistic or not. In this way, it is believed that the participation of individuals with ASD in society provides opportunities for interaction to benefit not only their development but also the concept of belonging.

Research on "Autism Spectrum Disorder: Difficulties for effective inclusion" is important both academically and socially. Understanding these aspects can improve inclusive practices and inform public policies, which will benefit not only autistic people but also society as a whole, as diversity promotes empathy and understanding. Understanding the needs of these individuals improves inclusion strategies. Therefore, this research has the potential to contribute significantly to the inclusion and well-being of individuals reported with ASD.

METHODOLOGY

The methodology adopted for this research will be qualitative-quantitative, which will have as an instrument a questionnaire directed to the responsible person and/or caregiver of the individual with ASD, regardless of gender and education, aged between 07 and 20 years old, and then the participants' answers will be interpreted. The qualitative-quantitative approach that will be employed to capture the perceptions and experiences of the guardians and/or caregivers of the individuals with ASD will be regarding the inclusion of individuals with ASD.

The questionnaire will be applied online through the form available at the link https://docs.google.com/forms/d/e/1FAIpQLSfyVUGD8sfdUDk-SUkuJNZjJfboboDGt6cb7bO5HsiLP-WNyg/viewform?usp=sharing.

DEVELOPMENT

The present survey consists of 32 questions, organized into four main sections: identification, family, school, and society. The development of this study was carried out through a multidisciplinary approach, which included the reading and analysis of scientific articles, specialized books, and relevant news on the subject. In addition, conversations were held with individuals directly involved in the theme of autism, as well as meetings with the collaborators responsible for the preparation of the research, ensuring a solid and grounded construction.

FINAL CONSIDERATIONS

The preliminary results of this research offer an initial overview of the perceptions and challenges faced by guardians and/or caregivers of individuals with Autism Spectrum Disorder (ASD). Based on the 32 questions distributed among the sections of identification, family, school and society, the following trends were observed: Identification of guardians: the data indicate that most of the people responsible for care are mothers in the age group of 30 to 44 years, married, with complete higher education and average income between 2.5 minimum wages. About the inclusion of the person with ASD in the family: in Brazil, 47% of families include totally, 39% partially, and 14% do not. When analyzing the regions of Brazil, it is noted that families in the Northeast region are the most inclusive, with 75% of total inclusion, followed by the Midwest, with 63% of inclusion. The North and Southeast regions are practically tied, with 42% and 43% of total inclusion, respectively. The South region, despite having the lowest percentage of total inclusion (35%), was the region with the lowest percentage of non-inclusion, as most families in the South region partially include it.

The changes that occurred in the family after receiving the report, for the most part, were positive. School: 25% manage to include effectively, 64% partially, 8% do not include, and 4% do not apply. Finally, in society, a high level of misinformation about what Autism Spectrum Disorder is has been identified."

REFERENCES

1. BRAZILIAN AUTISM ASSOCIATION. Definition. 2024. Available at: https://www.ama.org.br/site/autismo/definicao/. Accessed on: 17 Feb. 2024.

2. AMERICAN PSYCHOLOGICAL ASSOCIATION. Autism Spectrum Disorder. 2024. Available at: https://dictionary.apa.org/autism-spectrum-disorder. Accessed on: 17 Feb. 2024.

3. BAPTISTA, C. R.; OLIVEIRA, A. C. Autism and education: reflections and intervention proposals. Porto Alegre: Artmed, 2002.

4. SANTOS, C. F.; SANTOS, H. C. D.; SANTANA, M. J. The learning process of autistic children. FSLF, 2016. Available at: http://fslf.edu.br. Accessed on: [insert date of access, if available].

5. BEYER, H. O. Inclusion and evaluation in school of students with special educational needs. Porto Alegre: Meditation, 2005.

6. BOSA, C. A. Autism: current interpretations for old observations. In: BAPTISTA, C. R.; BOSA, C. A. (ed.). Autism and education: reflections and intervention proposals. Porto Alegre: Artmed, 2002. p. [insert pages, if available].

7. BUCHOLZ, J. L. Social Stories for children with Autism: a review of the literature. Journal of Research in Education, [s.l.], see [insert volume], n. [insert number], p. [insert pages], 2012. Available at: https://files.eric.ed.gov/fulltext/EJ1098400.pdf. Accessed on: [insert date of access, if available].

8. CHAN, J. M.; O'REILLY, M. F. A Social Stories™ intervention package for students with autism in inclusive classroom settings. Journal of Applied Behavior Analysis, [s.l.], v. 41, n. [insert number], p. 405-409, 2008. DOI: https://doi.org/10.1901/jaba.2008.41-405.

9. KUOCH, H.; MIRENDA, P. Social Story interventions for young children with Autism Spectrum Disorders. Focus on Autism and Other Developmental Disabilities, [s.l.], v. 18, n. 4, p. 219-227, 2003. DOI: https://doi.org/10.1177/10883576030180040301.

10. KRISTEN, R.; BRANDT, C.; CONNIE, K. General education teachers' relationships with included students with Autism. Journal of Autism and Developmental Disorders, [s.l.], v. 33, n. [insert number], p. [insert pages], 2003.

11. LORIMER, P.; SIMPSON, R.; MYLES, B. S.; GANZ, J. The use of Social Stories as a preventative behavioral intervention in a home setting with a child with Autism. Journal of Positive Behavior Interventions, [s.l.], v. 4, n. 1, p. 53-60, 2002. DOI: https://doi.org/10.1177/109830070200400109.

12. MARFINATI, A. C.; ABRÃO, J. L. F. A journey through child psychiatry: from historical antecedents to the origin of the concept of autism. Styles of the Clinic, [s.l.], v. 19, n. [insert number], p. [insert pages], 2014.

13. WORLD HEALTH ORGANIZATION. ICD-11 – Classification of mental and behavioral disorders: clinical descriptions and diagnostic guidelines. [S.l.]: WHO, 2022.

14. SCHILLING, F.; MIYASHIRO, S. G. How to include? The debate on prejudice and stigma today. Educação e Pesquisa, São Paulo, v. 34, n. 3, p. 567-580, 2008. Available at: https://www.scielo.br/j/ep/a/dPKVFyfN6PDnQFkFsJ7P4wK/?lang=pt. Accessed on: [insert date of access, if available].

15. SELLA, A. C.; RIBEIRO, M. D. Behavior analysis applied to autism spectrum disorder. Curitiba: Appris, 2018.

16. CAMPOS, R. C. Autism Spectrum Disorder – ASD. In: Clinical sessions in network – technical update. [S.l.]: [s.n.], 2019. p. [insert pages, if available].

17. STEINBRENNER, J. R.; HUME, K.; ODOM, S. L.; MORIN, K. L.; NOWELL, S. W.; TOMASZEWSKI, B.; SZENDREY, S.; MCINTYRE, N. S.; YÜCESOY-ÖZKAN, S.; SAVAGE, M. N. Evidence-based practices for children, youth, and young adults with Autism. Chapel Hill: The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team, 2020.

18. THIEMANN, K. S.; GOLDSTEIN, H. Social Stories, written text cues, and video feedback: effects on social communication of children with Autism. Journal of Applied Behavior Analysis, [s.l.], v. 34, n. 4, p. 425-446, 2001. DOI: https://doi.org/10.1901/jaba.2001.34-425.