Analysis of Educational Quality for People on the Autism Spectrum: A Review of the Literature

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Abstract - The objective of this research was to determine, through a review of the literature, the perception of parents of children with autism spectrum disorder on the quality of education for people with this disorder in Lambayeque. The research was of a mixed type. A sample of 80 parents was considered. For data collection, a previous interview was carried out, followed by the application of a questionnaire. The results indicate that 48% of the sample disagreed on the correct implementation of early intervention programs; 54% of the participants disagreed on whether it is easy for their child to attend school. Fifty-eight percent of the sample totally disagreed on whether teachers are trained to attend to children with ASD at school. Finally, a negative perception of the is evident, since they indicated that they totally disagree with the process of quality and accessibility to education, programs, etc. for children with ASD.

Keywords: Education, Autism Spectrum Disorder, Parents

I. INTRODUCTION

Autism Spectrum Disorder (ASD) can have a significant impact on students as it affects various aspects of development, communication and social interactions. The challenges associated with ASD can vary widely among individuals, as the disorder manifests itself differently in each case.

Internationally, the World Health Organization (WHO) estimates that approximately 1 in every 160 children worldwide (0.625%) has an Autism Spectrum Disorder (ASD). Research in the United Kingdom indicates that the percentage of children and adolescents affected by ASD is around 1%, being more prevalent in boys than in girls. Since this disorder has no cure, its impact affects adults in a similar proportion to that of children. In this context, it is estimated that around 700,000 people are living with ASD in the UK.

If the family environment is considered, ASD is part of the daily lives of approximately 2.8 million people (Lampert, 2018).

The estimate provided by the United States Centers for Disease Control and Prevention (CDC), highly recognized entity in the collection of specialized information and health statistics, indicates that there is currently one case of autism for every 68 births. This figure suggests an annual increase in incidence of 17%, being 5 times more common in males than in females (Celis & Ochoa, 2022). According to Vidyashree et al., (2019) the global frequency of Autism Spectrum Disorder (ASD) is on the rise, and although the precise reasons for this increase are unknown, the literature indicates that, worldwide, at least one in 160 children has ASD, a figure that exceeds the prevalence of Down syndrome by five times.

In Latin America, the prevalence of autism spectrum disorder (ASD) is between 25 and 30 people per 10,000 inhabitants, according to information collected between 2011 and 2013. Suspicions about the disease usually arise when the child reaches 18 months of age, and the definitive diagnosis is obtained, on average, at around four years of age. The professionals in charge of making the diagnosis are usually psychologists, neurologists or psychiatrists (Morocho et al., 2021).

Nationally, in Peru, approximately 15,625 individuals have Autism Spectrum Disorder (ASD), 90.6% of whom are under 11 years of age. This disorder of the neurodevelopment causes challenges communication, social interaction and also leads to increased interest in certain topics or routine activities (MINSA, 2019).

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Generally speaking, due to the particular circumstances of people on the autism spectrum and their families, certain countries have established regulations with the aim of safeguarding their rights in social, health and educational áreas (Khodjaev et al., 2024). This approach is observed, for example, in countries such as Argentina, Chile and Mexico. In contrast, other nations such as Spain and England have implemented direct state strategies and programs to support the inclusion and comprehensive care of people with autism (Lampert & Méndez, 2023; Autism and education-Autism Spectrum Disorder, 2020).

In Peru, Law N°30150, establishes a legal regime that promotes early detection and diagnosis, early intervention, health protection, comprehensive education, professional training and labor and social insertion of people with autism spectrum disorder (ASD), under the provisions of Article 7 of the Political Constitution of Peru and Law 29973, General Law on Persons with Disabilities (CONADIS, 2015).

In relation to the statistics of people with ASD who have access to education, the Confederación Autismo España

In reference to parents of children with Autism Spectrum Disorder (ASD), they express their perception that there is a lack of educational personnel specialized in understanding autism (Stefanov, 2018; Hajjaji & M'barki, 2018). They consider that this small group employs hierarchical and top-down approaches, disregarding the opinions of those with direct experience in knowing these children, such as parents themselves, classroom assistants or other non-teaching members. Given that parents or caregivers are not specialists in all areas related to autism, the need for specialized guidance from involved professionals is highlighted. However, during the intervention process, the importance of taking into account the goals, needs, and opinions of those who live with these children to family interactions is emphasized (Valdez & Cartolin, 2019).

This study sought to understand the perception of families with with Autism Spectrum Disorder (ASD) on the importance and satisfaction of their needs, as well as their relationship with the sense of belonging and the perception of discrimination in the educational environment. Fifty-five mothers and fathers in the Autonomous Community of the Canary Islands with children between 4 and 12 years of age with ASD were analyzed. Five critical needs with low frequency of satisfaction were identified, and cluster analysis The results of this case study were used to examine the perception of three parents and three teachers about the process of school inclusion in educational institutions in Santa Marta, Colombia, for children with Autism Spectrum Disorder (ASD). The results indicate benefits for children with ASD in terms of cognitive and behavioral improvements. However, deficiencies in the process were identified, such as the lack of flexibility and curricular adaptability, as well as the insufficient adaptation of spaces and didactic resources to the specific needs of this population.

reports that to date, students with autism represent 28% of the student population (*Autismo y educación - Trastorno del Espectro Autista TEA*), 2020; Shanmugam et al., 2017).

According to information provided by the Ministry of Education (Minedu), at the beginning of the 2023 school year, 6 thousand students diagnosed with Autism Spectrum Disorder (ASD) joined the educational system (Malhotra & Iyer, 2024). The World Health Organization highlights that the main characteristic of these students is their challenge to socialize and establish relationships (El Comercio, 2023).

As mentioned by Valdez & Cartolin, (2019), educational integration involves achieving a balance between quality learning and school performance consistent with the student's abilities, thus ensuring a meaningful educational experience for all. In this context, it is important to understand the challenges faced by children with Autism Spectrum Disorder (ASD), as well as the health interventions that address these difficulties and improve their performance to facilitate the appropriate acquisition of knowledge in the school environment.

delineated two types of families according to the satisfaction of their needs. Sense of belonging and perception of discrimination differentiated these groups, with the cluster with the highest need satisfaction showing the best results. These results highlight the importance of families' perception of their needs and provide insights for interventions aimed at improving the well-being children with ASD and their families. Likewise, Toledo & Basulto, (2020) in their article seek to analyze the social representations of the educational experience of young people with Autism Spectrum Disorder (ASD) through the life stories of their mothers. The qualitative study, framed in an interpretive and phenomenological paradigm, included five mothers of young people with ASD in Concepción, Chile, using a thematic categorical content analysis. The results highlight the lack of preparation and willingness of regular education teachers to work with students with ASD, in contrast to the positive and empathetic attitude of other students (Debbarma & Praveen, 2019). Mothers express concern about the lack of school integration and fear for the future of their children due to legislation. The article explores representations of discrimination, lack of integration and a denied educational future. In addition, Badillo et al., (2022) carried out a descriptive study

Also, García et al., (2022) in their research sought to evaluate the accessibility and satisfaction in health and education services, as well as the economic and family impact, stigma and quality of life of people with Autism Spectrum Disorder (ASD) and their families. The sample included 291 caregivers, mostly mothers, of 291 people with AS, mostly males between the ages of 1 and 40 years. The results indicate insufficient and unspecified access to health services, as well as significant economic challenges for families. The survey highlights the existence of stigma and discrimination,

highlighting the need to implement collaborative strategies to improve the quality and accessibility of services and reduce the economic and mental health burden for families.

In national research, Sumalavia & Almenara, (2018), analyzed the adaptation of parents with children diagnosed with autism spectrum disorder (ASD) using the ABCX Dual Model of Family Adaptation. Seven parents (five mothers and two fathers) whose children were receiving care in specialized institutions in Lima participated. Using a qualitative approach and semi-structured interviews, feelings linked to the diagnosis were identified, highlighting the influence of professional care and information about ASD. The importance of social support and the need for professional assistance to face challenges was highlighted. In conclusion, the usefulness of the model to understand this process was underlined and the need to provide information and specialized care to foster positive family adaptation and promote the well-being of people with ASD and their families was emphasized.

That is why this study aims to know the perception of parents of children with ASD about the quality and access to education of their sons or daughters (El Comercio, 2023). This is of utmost importance because it provides a holistic and experiential view that is essential to improve the quality and access to education for children with ASD, thus contributing to a more inclusive and equitable educational system.

II. MATERIAL AND METHOD

The research was of mixed type, it is defined as a methodological approach that combines qualitative and quantitative elements in the same study. This approach seeks to take advantage of the strengths of both methods to obtain a more complete and deeper understanding of the phenomenon under investigation (Hernández & Mendoza, 2018).

A population of 120 parents from the city of Lambayeque was considered, for the sample only 80 parents were selected (60 women and 20 men; between the ages of 28 to 50 years old), which were determined through a non-probabilistic sampling by convenience, that is, the sample was chosen directly and intentionally, selecting those to whom there is greater accessibility (Hernández & Mendoza, 2018). Therefore, inclusion criteria were established as those fathers and mothers who willingly decided to participate in the research through informed consent, and those who correctly completed the questionnaire and attended the previous interview were taken into account. Exclusion criteria were those fathers and mothers who did not attend the previous interview and did not come to the application of the survey or instrument.

For data collection, a previous interview was conducted, and then the application of a questionnaire, which was validated by expert criteria, it should be noted that the administration of the survey was face-to-face, after the application, the data was filled in a MS EXCEL V. 2019 sheet, and then analyzed using the statistical software SPSS V. 25, in which tables and graphs were obtained as results.

As for the ethical criteria, those established by the Belmont Report were taken into account. These principles include respect for persons, which implies recognizing the autonomy of individuals and obtaining their informed consent; beneficence, which requires maximizing the benefits and minimizing the risks for participants; and justice, which requires equity in the selection of participants and the fair distribution of benefits and burdens (Belmont Report, 1978).

III.RESULTS

TABLE I PERCENTAGE OF PARENTS WHO CONSIDER THAT EARLY INTERVENTION PROGRAMS ARE IMPLEMENTED CORRECTLY

Items	N°	%
Strongly disagree	27	34%
Disagree	38	48%
No opinion	5	6%
Agreed	7	9%
Totally agree	3	4%
Total	80	100%

Note: Survey applied to parents of people with ASD.

It is observed that the majority of parents with ASD disagree that early intervention programs are implemented correctly, while 9% indicate agreement.

TABLE II PERCENTAGE OF PARENTS WHO CONSIDER THEIR CHILD'S SCHOOLING EASY

Items	N°	%
Strongly disagree	43	54%
Disagree	28	35%
No opinion	3	4%
Agreed	5	6%
Totally agree	1	1%
Total	80	100%

Note: Survey applied to parents of children with ASD.

It is observed that the majority of parents with ASD disagree that it is easy for their child's schooling, while 6% agree.

TABLE III PERCENTAGE OF PARENTS WHO CONSIDER THAT TEACHERS ARE TRAINED TO DEAL WITH CHILDREN WITH ASD AT SCHOOL

Items	N°	%
Strongly disagree	46	58%
Disagree	30	38%
No opinion	1	1%
Agreed	2	3%
Totally agree	1	1%
Total	80	100%

Note: Survey applied to parents of children with ASD.

It is observed that the majority disagrees that teachers are trained to attend to children with ASD at school, while 3% agree.

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TABLE IV PERCENTAGE OF PARENTS WHO CONSIDER THAT ACCESS TO OUT-OF-SCHOOL PROGRAMS FOR PEOPLE WITH ASD IS RESTRICTED

Items	N°	%
Strongly disagree	15	19%
Disagree	18	23%
No opinion	10	13%
Agreed	22	28%
Totally agree	15	19%
Total	80	100%

Note: Survey applied to parents of people with ASD.

It is observed that the majority of respondents agree that access to out-of-school programs for people with ASD is restricted, while 23% disagree.

IV. DISCUSSION

The objective of this research was to know the perception of parents of children with ASD about the quality and access to education for their children, according to the survey applied, it was found that most parents state that it is very complex to access education for children with autism spectrum disorder, this is reflected by answers of the questionnaire applied to the sample.

The first question on whether they consider that early intervention programs are implemented correctly, 48% of the sample expressed disagreement, that is, that early intervention programs are not implemented in an adequate way. This is similar to what was found by Sumalavia & Almenara, (2018), who emphasize the need to provide information and specialized attention to foster positive family adaptation and promote the well-being of individuals with ASD and their families. In addition, Curra et al., (2023) highlight the importance of families' perception of their needs and provide insights for interventions aimed at improving the well-being of children with ASD and their families.

In relation to the second question about whether parents consider that it is easy for their child's schooling, 54% of the participants evidenced total disagreement, which indicates that it is complex for children with ASD to access schooling, this is similar to what was found by Badillo et al., (2022) who identified deficiencies in the schooling process of children with ASD, such as the lack of flexibility and curricular adaptability, as well as the insufficient adaptation of spaces and didactic resources for the specific needs of this population. Also Valdez & Cartolin, (2019), refer that educational integration implies achieving a balance between quality learning and school performance consistent with the student's abilities, thus ensuring a meaningful educational experience for all.

Regarding the third question on whether parents consider that teachers are trained to care for children with ASD at school, it was found that 58% of the sample are in total disagreement, which shows that most teachers do not have the necessary skills to provide care to children with this disorder, this is

complemented by Valdez & Cartolin, (2019), who state that parents of children with Autism Spectrum Disorder (ASD) express their perception that there is a lack ofeducational personnel specialized in understanding autism. They consider that this reduced group employs hierarchical and vertical approaches, without taking into account the opinions of those with direct experience in the knowledge of these children, such as the parents themselves, classroom assistants or other non-teaching members. Likewise, Toledo & Basulto, (2020), highlight the lack of preparation and willingness of regular education teachers to work with students with ASD, in contrast to the positive and empathetic attitude of other students.

The fourth question on whether parents consider that access to non-school programs for people with ASD is restricted, most of the sample showed (28%), i.e., this group of parents identified restrictions to access non-school programs for children with ASD. This is confirmed by García et al., (2022), who highlight the existence of stigma and discrimination in access to education, highlighting the need to implement collaborative strategies to improve the quality and accessibility of services and reduce the economic and mental health burden for families.

Finally, the conclusions on the research show a negative perception of parents, since they indicated that they totally disagree with the process of quality and accessibility to education, programs, etc. for children with ASD, which shows the complexity of the procedures they have to carry out so that their children with a diagnosis of autism spectrum disorder can have access to quality education and the necessary attention to intervene with each of them.

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