

Chapter #29

THE FUNCTIONALITY PROFILE OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS (ASD) IN THE AZORES – COMMUNICATION, LEARNING AND AUTONOMY

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ABSTRACT

Autism is a disorder of the neuro-development characterized by persistent difficulties in communication, cognitive processes, social interaction and also by restrict interests and repetitive and stereotyped behaviours. Regarding to the vision of Universal Design for Learning (UDL), the educational approach should enhance not only the academic acquisitions but also the prognosis of the evolution of the clinical condition and of the functionality of children with Autistic Spectrum Disorders (ASD). Thus, it was considered important to know the perspective of educators / teachers and parents / guardians for the 121 children with ASD who participated in this study.

These children, aged 3-11 years old, live in the Azores (ARA) and are enrolled in kindergarten and in primary schools. Data were collected with a questionnaire (educators/teachers) and in an interview (parents/caretakers). Results suggest that there are different perspectives between the two groups, with educators/teachers viewing the functionality profile of these children as being more aggravated. These differences are statistically significant, especially in terms of the functionalities assessed by the items of communication and learning. The analysis of these different perspectives evidences the importance of the communication between these educational providers regarding the work developed by them.

Keywords: autism, functionality, family, school, universal design for learning.

1. INTRODUCTION

1.1. Autism spectrum disorder

According to the American Psychiatric Association, Autism Spectrum Disorder (ASD) have as their etiology a central nervous system disorder whose manifestations affect a child's normative development. These symptoms may appear during the first 3 years of life, affecting interpersonal communication, social interaction, and interests, causing repetitive behavior and, therefore, impairing the daily functioning of children (APA, 2013).

In regard to the worldwide prevalence of this pathology, it is estimated that it is at least 1.5% in developed countries, with recent increases, especially in cases where there is no associated intellectual deficit (Lyll et al., 2017). Studies related to the epidemiological profile of the ASD, such as Reis, Neder, Moraes and Oliveira (2019), report a higher frequency of diagnoses in males (77%), compared to females. Regarding the age group, there was a greater occurrence in the 5-8 years (44%), followed by the 9-12 years (29%),

13-16 years (15%), 1-4 years (11 %) and between 17-20 years (1%). As for education, most of these children attended primary (49%) and pre-school (33%) education. In 18% of the cases, they did not attend school.

This clinical dysfunctionality is mainly reflected in resistance to common teaching methods and changes in routine. It may also involve cognitive impairment, changes in sleep patterns, difficulties in establishing eye and physical contact with others, difficulties in playing symbolic and “make-believe” games, fascination or obsession with specific subjects, hyper or hypersensitivity to auditory, visual and tactile stimuli, intense motor activity, among others (Lobo, 1998). To recognize all these characteristics is also to understand that children with ASD need differentiated educational responses and that providing the necessary support simultaneously promotes the acquisition of learning and optimizes communication and socialization skills (Pereira, 2008). In 2001, the World Health Organization made it possible to understand the ASD through a biopsychosocial and integrated model of human functionality and disability - the International Classification of Functioning, Disability and Health - Children and Youth (ICF-CY). This Classification served the purpose of standardizing the language on the subject and allowed educational, health, and rehabilitation professionals to describe the functionality profiles of children up to 18 years of age by assessing development and behavior in dimensions such as communication, learning, and autonomy (CPDEC, n.d).

1.2. Communication, learning and autonomy in autism spectrum disorder

ASD is usually diagnosed during early childhood and is characterized by a triad of symptoms that includes the presence of a compromise in the quality of social interactions associated with the existence of deficits in interpersonal relationships, a delay in the development of communication and, furthermore, the presence of restrictive interests and / or repetitive movements (body stereotypes) (APA, 2013; Who, 1993). In addition to these characteristics designated by essential criteria for the diagnosis of ASD, these individuals can frequently present significant comorbidities such as: intellectual deficits (Matson & Shoemaker, 2009; Matson et al., (1996), psychiatric conditions (White, Oswald, Ollendick & Scahill, 2009), delay or atypical development of motor behaviors (Green et al., 2008) and difficulties related to the abilities to imagine. It is common to see that these symptoms persist throughout life, vary and influence, in the long run, the individual's development potential and independence (Sigafos, Roberts-Pennell & Graves, 1999).

Research unanimously refers to changes in communication and language as the main factors of ASD and as having a strong impact on the quality of these individuals' social interaction and behavior (Fernandes, 1994). This communication deficit also reflects a severity spectrum that can range from the total absence of communication to fluent language (Oliveira, 2005). However, what characterizes the communication profile of individuals with ASD, even the high functioning ones, is the existence of deficits in the level of social pragmatics and in the comprehension of language as a whole. The delay in the development of expressive language, and even its absence, is one of the main reasons for clinical referral.

The learning profile of children with ASD is related to the various cognitive abilities that these children may have, ranging from deep mental disability to higher intelligence (Abreu, 2013). Children with ASD may be more frequently impaired in four specific areas of cognition: imitation, social interaction, play and skills, and ability to develop “theory of mind” skills (Brown & Whiten, 2000). According to Ortiz (2005), ASD children have cognitive rigidity. Given this characteristic, and in order to facilitate learning processes,

these children benefit from learning based on concrete and contextual stimuli (Mota, 2008). The resistance to change and new learning also has its origin in the children's limited imaginative capacity and symbolic play, what can have negative repercussions on their development of conceptual structures and in the ability of solving problems of a symbolic nature, such as calculus, reading and writing (Hewitt, 2006)

Autonomy is a process that begins in the early years of the individual's life and develops throughout life (Silva, 2015). This ability for an individual's personal, domestic and social performance is one of the most important achievements in attaining their social independence. Thus, it is essential to evaluate the adaptive behavior that characterizes this domain of the personal development of children with ASD (Oliveira, 2005). According to Oliveira (2005), results from the application of the Griffiths Mental Development Scale in children with ASD show low rates in the areas of language and practical reasoning and higher rates in the areas of achievement, global motor skills and social staff (autonomy). However, individuals with ASD have a significantly lower environmental adaptive capacity when compared with groups of other individuals without ASD (Oliveira, 2005).

1.3. The contribution of the universal design for learning (UDL) in the learning of students with autism

Universal Design for Learning (UDL), developed by the Center for Special Applied Technology (CAST), takes a contemporary stance in the development of innovative approaches, with the aim of creating universal access to educational curricula for all students, including students with disabilities. This methodology adopts the purpose that all school environments reduce the barriers that hinder the learning of the curricular plan. To this end, the DUA methodology advocates the exercise of flexible teaching approaches and the teaching of meaningful learning to students (Meyer, Rose, & Gordon, 2014).

Meyer et al. (2014), CAST co-founders, assume that there is no single way of learning. The theoretical framework of DUA presents some guidelines for the development of curricula, which include: (a) multiple means of representing content in order to allow students to acquire knowledge; (b) multiple means of action and expression so that students can demonstrate their knowledge, the learning achievements and (c) multiple means of participation and involvement, considering their interests and motivations, in presenting new challenges in their curriculum (Denning & Moody, 2013).

This methodology has been recognized as an asset in supporting the inclusion of students with special educational needs, such as students with ASD. Denning and Moody (2013) report that the principles of the UDL methodology are very valid responses in adapting the classroom environment, as these students may find it difficult to maintain attention, filter out unnecessary information and the ability to change the attentional focus. Another concern to address concerns the need to adapt the presentation of content considering the limitations that these students may feel at the level of information processing or even regarding the requirement for cognitive flexibility (Goldstein, Johnson & Mineshew, 2001). The concept of self-involvement, considered of great importance in the UDL, is also one of the main objectives to consider when including a student with ASD in the classroom, especially since routines are an important factor for the adequacy of their behavior and for the consolidation of learning (Mancil & Pearl, 2008).

According to Mcleskey and Wldron (2007), effective inclusion fits into the UDL methodology given that, as this theory predicts, support for students with special educational needs in the classroom should be discrete. That is the only way they can feel naturally belonging to a school context. According to these authors, teachers should use supports and teaching methods that are effective for all students.

Ultimately, and from the perspective of Denning and Moody (2013), the application of UDL in pupils with ASD may represent an advance in improving school achievement as this approach promotes understanding, independence and performance of these children. The same authors point out that the principles of UDL include the use of supports for routines and procedures, the preparation / anticipation of material and subjects that can assist in the selection of content that constitutes meaningful learning related to skills and previous knowledge of the students; also the use of visual clues (such as symbols or photos) and other tools that increase the forms of representation, and the use of structured tools for the analysis and expression of content; finally, as a primary advantage, to consider and value the interests of the student, with a view to enhancing their involvement and active participation.

1.4. Importance of school-family articulation

In the school context, teachers try to know and understand the student through what he shows him directly, however he must also understand him in the light of a systemic perspective, that is, behind each student there is a family made up of several members, with their values, functioning and material and emotional needs (Carvalho, 2017). Thus, when a student enters school, he should not be considered as an individual, but as someone inserted in a cultural, social and family context (Reis, 2012).

In fact, the school context as well as the family context must remain linked and predisposed to share information they have, in order to act together in the success of the development of the child's cognitive and social skills, this involvement of the parents in the child's educational process with special educational needs (SEN), as is the case with children with Autism Spectrum Disorder (ASD), assumes an even more fundamental character for their educational success (Reis, 2012). Nevertheless, Reis (2012) states that there is a willingness of parents to get involved in their children's educational practices, but that many of them do not know how to do it, do not have the time available and / or refer that the school does not encourage this involvement and participation. Carvalho (2017) understands the notable difference in terms of the nature of each of these two contexts mentioned above, however the author stresses that both have very similar objectives and concerns with regard to their students and, for this reason, the school context should create the conditions necessary to foster frequent contact with the families of their students.

In addition to a curriculum that considers the needs of children with ASD and values their interests, the articulation between the School and the family system is equally relevant. Success in acquiring the different stages of the process of communication, learning, and autonomy of a child ASD is closely related to their skills, but also with the attitude and skills of their family members to face of this disturbance (Gomes, 2013). The birth and growth of a child with neurodevelopmental problems encourage parents to accept their condition, and to seek to apply the responses that best fit their child's real needs and abilities (Gomes, 2013). Likewise, according to Gomes (2013), it is of great importance that parents share information about the child to school so that the institution meets the necessary conditions for the promotion and enhancing their skills. Similarly, it is essential that these families, as well as schools, are aware of the importance of implementing strategies that enhance the development of communication, learning, and autonomy, and where students perform domestic tasks, solve problems and are stimulated in negotiation skills as a way of promoting responsibility and self-control (Silva, 2015).

The coordination between the school and the families of children and/or young people with special educational needs should also take into account the fragility that this type of family system experiences, with a great tendency towards social isolation that makes these

families often have difficulties in taking the initiative to address and articulate with the school (Carvalho, 2017). In order to be able to promote resilience in a child, especially those with SEN, it is first necessary to work on the resilience of their families, through guidance, emotional support and psychological support, so that they feel able to interact and educate their children (Carvalho, 2017). Guidance should occur because, generally, this type of families, given the emotional overload they feel and the consequent social isolation, are often little and / or inadequately informed about the best procedures to be carried out to satisfy emotional, social and educational needs for their children. For this reason, the articulation between schools and families of children and / or young people with SEN is crucial and inevitable, where formal and / or informal meetings should be given priority, providing these families with pedagogical guidance but also emotional and psychological support. (Carvalho, 2017).

A close sharing relationship between family and school is a fundamental factor for the good prognosis in the evolution of the functionality of children with neurodevelopmental disorders (Martins, Acosta & Machado, 2016).

2. METHODOLOGY

The present study started in 2017, with data collection and dissemination of results taking place in 2019.

The first stage was to carry out a review of relevant literature on the different topics covered, with a view to the elaboration of data collection protocols, through two structured interviews addressed to the parents and to the teacher (s) / educator (s) of the student diagnosed with ASD.

This investigation, called the Epidemiological Study of the ASD in the Azores assumed as a general objective:

Assess and update the Azores data regarding the prevalence of children diagnosed with ASD, from 3 to 11 years of age, who were enrolled in kindergarten and in the 1st cycle of basic education. Given the vast selection of variables under study, which make up the data collection protocols, the following objectives were also defined as specific objectives of this study:

Characterize the functional profile of children with ASD in pre-school and school age living in the Azores, from the perspective of caregivers;

To characterize the functional profile of children with ASD in pre-school and school age living in the Azores, in the perspective of the educator (s) / teacher (s);

Characterize the impact of the diagnosis on the family of the child with ASD, regarding psychological well-being; Personal-Social and material.

In the case of this article, in specific, the procedures will be described and the data related to the first two specific objectives, mentioned above, will be presented.

After a positive opinion by the Ethics Committee of the University of the Azores and the Regional Directorate for Education of the Azores, the research team initiated contacts with the Executive Councils and Directive Councils, for the application of the Education Protocol and the Family Protocol, in the Organic Units (30), Private Schools (8) and Kindergartens of the Network of Public Institutions of Social Solidarity (PISS) (40) of the entire Azores.

All the parents who consented to participate in this investigation signed an informed consent document that guaranteed the anonymity and confidentiality of the information obtained.

Together with all of the top departments for these educational institutions, the number of children enrolled, per cycle, within the age groups that the study comprises was determined, as well as the number of children diagnosed with ASD, for the purposes of treatment and statistical analysis of data.

The target population comprises 172 children with a diagnosis of ASD. It was used a sample of 121 children whose parents agreed to participate in the study, mostly boys (82%), the average age of 6 and a half years old. Half of the children have mildly severe ASD, 32% a moderate degree, 4% a severe degree, and 14% did not report.

The data were collected through structured interviews, based on a literature review on autism, instruments used in the identification and characterization of autism, and the variables of the International Classification of Functioning, Disability, and Health (ICF) in the domain of communication, learning, and autonomy. The interview with caregivers was composed of five dimensions: i) personal data of the child; ii) socio-family characterization; iii) clinical history; iv) functionality and participation profile; v) impact of ASD on the family. The interview with educators comprised three dimensions: i) data from the institution; ii) student's personal data; and iii) functionality and participation profile.

This study was previously submitted to the Regional Directorate of Education and to the Ethics Committee of the University of the Azores, having been issued by both entities in favour of its realization. The parents were also auscultated, through the respective educational institutions, who explained the nature and purpose of the study. Families who agreed to collaborate and consented to the consultation of their children's Individual Educational Programs (IEP) signed their Informed Consent. All collected data were entered into IBM SPSS Statistics, constituting a database with 121 rows, each of which refers to each case of ASD. Data were analyzed using some methods of Descriptive Statistics and the hypothesis test for the difference between two proportions, with the purpose of verifying whether the perceptions of the school and the family differ significantly or not regarding the functionality of the profile of children with ASD, with regard to communication, learning and autonomy.

2.1. Presentation and analysis of results

Tables 1, 2 and 3 present a summary of the results regarding the functionality profile of children with ASD, regarding, respectively, “Communication”, “Learning and Application of Knowledge” and “Autonomy” (self-care), from the perspective of educators/teachers and of parents/family/ caregivers. The last column of each table is concerning the hypothesis test for the difference between two proportions.

It was found that there are statistically significant differences ($p < 0.01$) between the perceptions of the school and the family regarding all items of functionality, associated with communication and learning, presented in tables 1 and 2.

Table 1.
Communication: Comparison between the two perspectives (%).

Communication	Does not do it alone/Some kind of disability		Statistic of test (Z)
	“School” Perception	Family Perception	
Communicate and receive oral messages	88.2	47.9	6.54*
Communicate and receive nonverbal messages	87.5	57.9	4.63*
Speak	82.4	52.1	4.85*
Produce nonverbal messages	86.4	57.9	4.31*
Conversation	92.1	63.6	4.76*
Discussion	91.5	62.0	4.45*
Use of communication devices	73.4	39.7	3.86*

* Difference is significant at the 0.01 level (2-tailed)

The biggest difference between both perspectives lies in the task of “Communicate and receive oral messages” and the smallest differences lie in the tasks of “Conversation” and “Produce nonverbal messages”. However, in both cases, school elements perceive greater difficulties.

Table 2.
Learning and Knowledge Application: Comparison between the two perspectives (%).

Learning and Knowledge Application	Does not do it alone/Some kind of disability		Statistic of test (Z)
	“School” Perception	Family Perception	
Observe	67.0	19.0	7.07*
Listen	59.8	20.7	5.84*
Imitate	75.8	22.3	7.90*
Learn By Interacting with Objects	71.4	20.7	6.38*
Acquire information	80.0	40.5	5.84*
Acquire language	82.7	50.4	4.97*
Rehearse (Repeat)	77.3	52.1	3.72*
Think	89.0	33.9	7.77*
Solve Problems	93.3	68.3	4.09*
Make Decisions	91.4	54.5	5.56*

* Difference is significant at the 0.01 level (2-tailed)

The biggest differences between both perspectives are in the items “Think” and “Imitate” and the smallest differences are in the items “Solve Problems” and “Rehearse”. However, both parts consider that the most significant difficulties are located in the areas of problem solving and decision making.

The autonomy skills were analysed in the light of self-care. The observation of Table 3 indicates that this is the area of greatest consensus between Educators/teachers and parents/family. In this context, it was found that there were no statistically significant differences between the perceptions expressed by the two parties regarding the items “Take care of body parts”, “Care related to excretion processes”, “Dress up”, “Take care of their own health”. However, significant differences were found between the perceptions of the two parties regarding the functionalities related to the items “Eat” ($p < 0.01$) and “Drink” ($p < 0.05$), with the school perceiving greater difficulties, compared to families.

Table 3.
Self-care: Comparison between both perspectives (%).

Self-care	Does not do it alone/Some kind of disability		Statistic of test (Z)	p
	“School” Perception	Family Perception		
Take care of body parts	57.4	69.4	-1.61	0.107
Care related to excretion processes	51.9	58.7	-0.96	0.338
Dress up	60.5	60.3	0.02	0.984
Eat	50.0	28.9	3.06	0.002*
Drink	31.7	17.5	2.38	0.017**
Take care of their own health	50.0	62.0	-1.26	0.209

* Difference is significant at the 0.01 level (2-tailed)

** Difference is significant at the 0.05 level (2-tailed)

The results of the present study prove the existence of a very different perspective about the skills of children with ASD, by caregivers and educators, mainly in the fields of Communication and Learning and Application of Knowledge. Although both perspectives identify limitations regarding the functionality of children with ASD, it is clear that caregivers have a more optimistic view of their children's skills. The average age of children in the sample, 6 years old, may partially explain these findings. It might be not easy for educators to find and implement teaching and interaction methodologies that overcome ASD's limitations

This brings us to the importance of practicing a teaching methodology such as UDL that enables these children to demonstrate their knowledge through multiple forms of expression and motivates them to achieve curriculum learning goals effectively and with significant involvement and participation. The positive results of this involvement in learning could contribute to cooperative work and closer communication between school and family, encouraging more realistic and objective expectations regarding the empowerment of children with ASD. In addition, it is important to increase training opportunities for professionals in various areas to improve their performance regarding the ASD.

3. CONCLUSION

The present work aimed to perform a characterization of the functionality profile of children with ASD in Azores, according to the perspectives of their educators / teachers and families. Children with ASD usually have significant difficulties in the areas of communication, socialization and behaviors. As such, it is essential to know not only the level of these limitations, but above all their areas of interest and their skills so that staff and family members can be successful in carrying out their mission. Pedagogical assessment and teaching methodologies with an emphasis on the active and motivated participation of these students can, according to current literature, contribute more efficiently to the optimization of these children as autonomous students and future youth and adults with a proactive role in society.

This study pointed out differences in the way parents and teachers think about children with ASD and their learning. Knowing these differences can be advantageous, for several reasons, namely for allowing a greater articulation between parents and teachers.

As limitations of the study, we identify the information collection instrument itself, which is used as an evaluation instrument in school contexts, and did not allow characterizing the sample profile regarding its areas of interest and motivations. Another weakness of this study was the failure to collect information regarding the methodology, strategies and learning support materials used by schools. Future research in this domain should improve data collection methods and contribute to optimizing the response in the areas of training, consulting and intervention within the scope of the ASD. It is also suggested to expand the study to other age groups.

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