

ANA PAULA ANTUNES ALVES

Fernando Pessoa University
Faculty of Social Sciences and Humanities, Portugal
ORCID: <https://orcid.org/0000-0003-0471-8370>
anapaulaalves@ufp.edu.pt

Autism Spectrum Disorders. What Intervention Methodologies Should We Select?

Zaburzenia ze spektrum autyzmu. Jakie metody interwencji należy wybrać?

Abstract. Considering that the child's development is a network of interactions between the family, peers, caregivers and society forces us to look at the child with differentiated skills using lenses with different perspectives. Such an approach implies a choice of both the instruments that are used to observe or intervene, and method of interpreting the child's behavior, which, while not following the typical development path, does not lose the features of being an actor acting on the basis of his own will, but also an organizer of his own actions, based on changes and their dynamics. Based on the ecological development theory, research was conducted to understand the perspectives of various actors (experts, professionals, parents) regarding educational intervention related to specific programs for students with autism spectrum disorders. Using the qualitative case study methodology, different views were noted that emerged in the narratives of children with autism spectrum disorders.

Keywords: child; autism spectrum disorders; methodology; intervention; case study

Abstrakt. Rozumienie tego, że rozwój dziecka to sieć interakcji między rodziną, rówieśnikami, opiekunami i społeczeństwem, skłania do spojrzenia na nie poprzez pryzmat soczewek o różnych perspektywach. Takie podejście implikuje wybór zarówno instrumentów, które są wykorzystywane do obserwacji czy interwencji, jak i sposobu interpretacji zachowań dziecka, które nie wpisując się w ścieżkę rozwojową uznawaną za typową, nie traci cech bycia aktorem działającym w oparciu o własną wolę, ale i organizatorem własnych działań bazującym na zmianach i ich dynamicie. Opierając się na teorii rozwoju ekologicznego, przeprowadzono badania, aby zrozumieć perspektywy różnych podmiotów (ekspertów, specjalistów, rodziców) w zakresie interwencji edukacyjnej związanej z określonymi programami dla uczniów ze spektrum autyzmu. Korzystając z jakościowej metodologii studium przypadku, odnotowano różne opinie, które pojawiły się w narracjach dzieci z zaburzeniami ze spektrum autyzmu.

Słowa kluczowe: dziecko; zaburzenia ze spektrum autyzmu; metodologia; interwencja; studium przypadku

INTRODUCTION

Special education teachers have, as a function, the individualization of educational strategies that can contribute to the autonomy of students facilitating their access to full citizenship. These functions involve the need to establish bridges between different disciplines simultaneously with careful listening to the voices that are part of the life project of individuals. In the face of students with autism spectrum disorders (ASD) it is a priority to know, in-depth, some of the specific intervention programs for ASD and relate them to the didactic and pedagogical issues that are emerging in the daily life of the educational intervention with these students.

Research in Portugal (Lima 2012; Oliveira et al. 2007) and international research (National Autism Center 2015) focus its concerns on the different specific programs for students with ASD referring to:

- evidence-based practices (Charman 2010; Reichow, Volkmar 2010),
- difficulties in articulating between theory and practice (Charman et al. 2011; Dingfelder, Mandell 2011),
- needs to monitor students' progress with ASD (Iovannone et al. 2003; Magiati et al. 2011).

With this conceptual framework, researchers tried to investigate the methodologies that are being used, in Portugal, from listening to the voice of those involved in an attempt to answer the question: What are the perspectives of the different actors – experts, professionals, parents – about the design, organisation and intervention of specific programs for students with ASD?

We have chosen to develop qualitative research (Marshall, Rossman 2011) since this is, in our opinion, the most appropriate to perceive the complexity of the action with an audience that, although it can be defined as belonging to the same category, mirrors among itself the singularity of the human being (Elo, Kyngas 2007; Koegel et al. 2011).

The case study format was used (Hays 2004; Stake 2009) in order to allow you to understand a particular phenomenon – specific programs for ASD and, at the same time, to be close to the subjects, to be able to hear their voices and access their interpretations of the daily life.

AUTISM SPECTRUM DISORDERS

Autism spectrum disorder is one of the terms used to describe a set of behaviors that manifests in a heterogeneous population group and are characterized by commitments in terms of social interaction, communication, and the presence of repetitive and restricted behaviors or interests (Bishop et al. 2008; Pinto et al. 2010; Charman et al. 2011; DSM-5 2013; Tuchman 2013). The coexistence of other conditions associated

with emotional and behavioral problems contributes to hinder the choice of the most appropriate intervention programs (Koegel et al. 2011). International studies estimate that there is a prevalence of 1% to 2% of children with ASD in Asia, Europe and North America (Centers for Disease Control and Prevention 2020).

REFERENCE THEORIES FOR AUTISM SPECTRUM DISORDERS

The description made by Kanner in the article *Autistic disturbances of affective contact* (1943) allowed to organize, in a specific concept, a set of behaviors with common characteristics, identify them as a disturbance of development and remove them from the area of mental illness where they were inserted until then.

Since then, many investigations have been carried out, focused on the set of behaviors that children in this group present trying, in different ways, to understand its etiology (Tuchman 2013), which biomarkers are valid for early detection (Walsh et al. 2011; Artigas-Pallarés et al. 2013), which is the most appropriate intervention for this heterogeneous disturbance (Lord et al. 2005; Odom et al. 2010; Magyar 2011). These investigations have given rise to theories that, over time, have led to different interpretations of ASD and functioned as support to support the intervention (Baron-Cohen 2008b; Lombardo et al. 2010; Oliveira 2010; Vismara, Rogers 2010; Lawton, Kasari 2013; Tuchman 2013).

Ecological theory of human development. Ecology is the study of the relationships between organisms and interaction contexts. In this perspective, Bronfenbrenner's bioecological model (1979) argues that the child's development is conditioned by the interaction of the biological part with the social environment where he evolves. Thus, when considering the child with ASD, we have to include the family, friends, school, as well as all the services that constitute the institutional and legislative geography that shapes the contexts they inhabit (Manitoba Education Research Network 2011).

Theory of mind. Our understanding of the situations we experience is based on a "mental tool that all adults [have] to a greater or lesser extent" (Frith 2006, p. 106). This ability, which theorists have called the Theory of Mind (ToM), is essential for an individual to be able to understand his behavior as well as the behavior of others (Begeer et al. 2011). ToM refers to the "competence to explain and predict behavior, based on hypotheses about the thoughts, emotions and objectives of partners in a social interaction" (Pisula 2010, p. 120).

Theory of executive functions. "Executive functions are neuropsychological processes involved in complex cognitive functions that include planning, cognitive and behavioral flexibility, inhibition and working memory" (Montgomery et al. 2013, p. 5). According to Frith (2006), the control of actions through executive systems is a very important area of neurosciences. This author points out that executive skills

are not necessary for routine actions such as walking or eating but are essential for us when it is necessary to perform tasks that are not usual.

Theory of central coherence. It refers to the tendency that children and adults, considered to have a typical development have to process information through attributes and meanings of general order and only then consider the particular aspects (Frith 2006). For Happé and Frith (2006), Frith (2006), Jolliffe and Baron-Cohen (2001) people who are part of ASD have difficulties in coherently integrating information not being able to have a general overview of a given situation.

Mindblindness theory. Baron-Cohen (1995, 2008a, 2008b) interconnects mindblindness theory with ToM and suggests that people who meet the criteria established for ASD may present “mental blindness” because, apparently, they are not able to adapt their behavior to the actions of others. According to this author, people who are part of the criteria of ASD, present commitments in the development of ToM revealing difficulty in continuing interaction actions with others.

Theory of empathy-systematization (Baron-Cohen 2008b). It explains the difficulties of communication and social interaction of people with ASD from the articulation between the level of empathy – understanding of the other, as opposed to competences in systematization – construction of systems and relationship between objects or subjects.

Theory of sociability in autism spectrum disorders. Ochs and Solomon (2010, p. 69) define “human sociability as a range of possibilities for social coordination with others that is influenced by individual dynamics or social groups”. For these researchers, the sociability of people with ASD can be considered as a possible form of social coordination. Understanding ASD is understanding what it means to relate to people and objects and what role the socio-cultural context plays to promote the articulation between joint care, harmony, intersubjectivity, and social coordination of feelings and actions (Ochs et al. 2004; Solomon 2012).

SPECIFIC INTERVENTION PROGRAMMES IN ASD

Specific programs are organized according to different conceptual models (Lord, Bishop 2010; Mulas et al. 2010; Charman 2010; Koegel et al. 2011) and have been analysed in the light of the concept – based on evidence.

Developmental programs. In this type of specific approaches the focus is on the construction, by the child, of positive and meaningful relationships with others and the development of social skills. They are structured programs with the typical development of the child as a model. The child is perceived from the competencies that emerge over time and the deviations to the development considered typical are noted, e.g. Floortime/DIR program.

Behavioral programs. ASD are perceived in terms of behavior or areas of competence and the analysis of excessive, inappropriate or altered behavior is made. These specific approaches are related to methods that interconnect environmental contingencies and behavior. The target behavior is identified, the intervention is applied and evaluated to verify the adequacy of the intervention, e.g. Applied Behavior Analysis Program (ABA).

Programs based on therapies. In this type of intervention, the focus of the program is the development of social or sensory communication. They are usually used as a complement to other interventions, e.g. Picture Exchange Communication System (PECS).

Combined programs. The focus is intervention directed to the characteristics of ASD. They incorporate behavioral, developmental and sensory strategies, e.g. the program Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH).

METHODOLOGY

Stake (2009) and Yin (2003) report that the case study is one of many ways of doing social research and that its use is justified in situations where questions of “how” and “why” are presented (Yin 2003) and in which the researcher intends to understand a certain phenomenon in a comprehensive way, close to the subjects and their contexts of interaction. This methodology is based on multiple sources of evidence (Ellingson 2009) and allows listening to the different voices that interact in a real context. These voices allow illustrating each of the programs from the narrative produced based on interviews with informants. According to Hays (2004, p. 218), case studies “seek to answer specific questions through the production of extensive descriptions involving multiple sources”. The descriptions stem from observation in context, from the analysis of documents, from interviews with subjects involved in the phenomenon under study.

Authors such as Denzin and Lincoln (1994), Merriam (1998), and Yin (2003), consider the case study as a comprehensive method of investigation that allows access to the voice of the other from an exhaustive description and a proposal of interpretation on what is said. For Creswell, Hanson, Plano and Morales (2007) this method is a qualitative approach to a case (person, school, program, etc.) or cases, with a delimitation in time and space using different sources of information (observations, interviews, documents, audiovisual material).

Yin (2003) recommends the use of some methods for data collection: observation, interviews, documents, archives, artefacts related to the phenomenon under study. The goal of using different sources is to achieve a deep understanding of the cases and give credibility to the study. We used some techniques considered in the area of social sciences as validation constructs of qualitative investigations (Hays 2004): we

considered triangulation and for this we used as a method the reading, by the interviewees, of the transcripts of the interviews to give feedback on what was transcribed, the reading of the official documents of the different programs.

The ethnographic narrative was also used as an element of critical reflection (Emerson et al. 1995; Hays 2004; Hsieh, Shanon 2005; Marshall, Rossman 2011) on the course of the investigation, guiding the data collection and recording of the inferences that have been made throughout the investigation process.

PARTICIPANTS

The choice of participants was intentional and the inclusion criterion in the study was the fact that they represented different levels of knowledge, both conceptual and practical, about the specific programs in ASD. It was important to listen to the voice of interlocutors with representativeness, in the approach to the phenomenon that we investigated. We looked for valid interlocutors, according to the perspective of Quivy and Campenhoudt (2008) who fell into the following categories:

- researchers and teachers,
- privileged witnesses,
- potential public of the study.

All participants in this study cover different universes of action and, in some way, have a fundamental role in understanding the phenomenon whether they are family, researchers, teachers or technicians.

DATA ANALYSIS PROCEDURES

In qualitative studies, data collection and analysis are constantly linked to interpretation issues (White, Marsh 2006; Marshall, Rossman 2011). To facilitate interpretation, we considered each of the interviews and the ethnographic narrative (Anderson 2010) as units of analysis (Graneheim, Lundman 2004) and, to access their understanding, we used the method of inductive content analysis (Elo, Kyngas 2008, p. 109). This method allows the use of “open source, category creation and abstraction” in the course of reading the documents. For Elo and Kyngas, open source means making notes and defining categories when first reading the narratives. These are then grouped into sets with a certain hierarchy and then the interpretations are elaborated.

Based on the data collected and using qualitative data processing methodologies, an inductive and deductive content analysis was made, seeking to find categories and highlight patterns from the interviewees' voice and ethnographic narrative (Yin 2003; Elo, Kyngas 2008). In Table 1 there are categories found from the interviews with the participants and the ethnographic narrative of the researcher.

Table 1. Categories from the interviews with the participants and the ethnographic narrative of the researcher

	Category	Description
Perspectives of the different actors on design, organisation and intervention in specific programs	Individual Educational Program	Fundamental element of the intervention's connection
	Generalization of intervention	There are many situations in which it is verified that the work developed is reflected in everyday life
	Program application	The contents worked are at the level of the problem areas of the students; solving problems; consider the motivation of students – intrinsic and extrinsic; intervention protocol
	Group	The maintenance of the group facilitates social interaction; in the same school as the brothers
	Future	Skills for the future; autonomy
	Multidisciplinary team	Collaboration between stakeholders and the existence of multidisciplinary teams
	Include	Attend the brothers' school; learn at school within the area of residence
	Time (duration)	People get scared when you talk about a 40-hour weekly schedule; he's at school all-day
	Tailor/oscillate/register	Development is not always linear or synchronous, the need to make a daily quantitative record to adapt the intervention plan; document the action
	Evaluate	Intervention, actions; data; assessment tools appropriate to ASD
	Early intervention	Start at the beginning; make a difference; early intervention is the possibility of making a difference

Source: own elaboration.

CONCLUSION AND RECOMMENDATIONS

The research we have carried out has allowed us to access different levels of knowledge about the reality of specific interventions for children with ASD. By listening to the voices of various people involved in the life project of these students it was possible to establish some bridges between research and practice. Parents, teachers, researchers, technicians, from the narrative they elaborated to answer the questions posed in the interviews, helped us to build a metanarrative on essential aspects of the intervention contributing to a reflexive questioning about appropriate practices with students with ASD, as other researchers (Pombo 2000; DeWalt, DeWalt 2002; Anderson 2010).

The possibility of listening to the different voices that participated in this study and, through them, understanding which points of intersection and distancing that is based on a certain philosophy of intervention contributed to a greater understanding of what is essential to consider in the choice of an intervention for people who fall under ASD (Lovaas 1981; Greenspan 1992; Schopler, Mesibov, Hearshey 1995; Correia 2013b).

The voices of the interviewees, in conjunction with the questioning made throughout the ethnographic narrative, allowed us to conclude that what is said and problematized by the participants does not deviate from the conclusions mentioned in national studies (Serrano, Pereira 2011; Lima 2012) and international studies related to the theme of pedagogical intervention (Lord et al. 2005; Charman et al. 2011; National Autism Center 2011; Boyd et al. 2013) revealing awareness of the constraints that arise in a specific intervention for people with ASD. It was also possible to observe that all the studied programs present, to a greater or lesser degree, strategies considered appropriate to respond to the characteristics of students with ASD, taking into account recent investigations (Lord, Bishop 2010; Tardif 2010; Charman et al. 2011; Dingfelder, Mandell 2011; Boyd et al. 2013; Tuchman 2013).

Tuchman (2013, p. 4) stated that “in face of a disturbing as heterogeneous as ASD, the invention needs to be redefined and conceptualized in an interdisciplinary neuro-evolutionary perspective”. Faced with this genetic and phenotypic heterogeneity, the intervention has to be established individually and in conjunction with a series of areas of knowledge to define, before that child, implicated in different contexts, to find the best intervention strategy. If there is no single etiology or a unitary explanation for this developmental disorder, it is also not possible to consider a single approach to ASD.

Most interviewees mentioned as essential that the approach or program should be supported by an interdisciplinary team given the heterogeneity of the disorder, its different subtypes, the different cognitive impairments, the existence of other associated pathologies that imply an intervention articulated with different areas of knowledge.

Considering the complexity of this disturbance and its framework in national dynamics (research, legislation, public and private organizations) and after the interpretation of the different narratives produced from the listening of those involved in this study, we can conclude that the implementation of specific intervention approaches or programs for students with ASD should consider a set of dimensions:

1. Family (Charman et al. 2011; Serrano, Pereira 2011; Correia 2013b). How is seen the crossing of the different dynamics, both of the family and of the contexts, in view of the needs of intervention? How the situation is assessed taking into account the cultures of belonging of each family and the unique aspects that characterize it and can condition the intervention?
2. Contexts (Portugal 1992; Fuentes-Biggi et al. 2006; Güemes-Carcaga, Martín-Arribas, Canal-Bedia, Posada-De la Paz 2009; Hume et al. 2011; Serrano, Pereira 2011). Different contexts of the child’s life (school, family, communities) are supported, considering that they may facilitate or hinder appropriate intervention.
3. Child (Barnbaum 2008; Bishop et al. 2008; Chawarska, Klin, Volkmar 2008; Auyeung et al. 2009; Baron-Cohen 2009; Howlin, Magiati, Charman, MacLean 2009; Klin 2009; Mulas et al. 2010; Ochs, Solomon 2010; Serrano, Pereira 2011; Gai et al. 2012; Artigas-Pallarés et al. 2013; Correia 2013a; Lawton, Kasari 2013). Consider the vision that each member of the team has of the child, what representations he

makes, how he listens to his voice. What should be evaluated? How it should be evaluated? What instruments to use? How is considered the individuality of each child? The child and his family – how to understand and respect interactions? What is the importance of promoting a sense of belonging and the beginning of the intervention? Early intervention is essential to enhance and develop autonomy and establish support networks in the different contexts of the child's life.

4. Programs (Greenspan, Lewis 2002; Stransberry-Brusnahan, Collet-Klingenberg 2010; Charman et al. 2011; Dingfelder, Mandell 2011; Hume et al. 2011; Koegel et al. 2011; Peters-Scheffer, Didden, Korzilius, Sturmey 2011; Reichow 2011; Ryan 2011; Warren et al. 2011; Gillespie-Lynch et al. 2012; Lima 2012; Boyd et al. 2013). What kind of dimensions to consider taking into account the specificity and uniqueness of each child, of each family? What is the most functional space/location? How to assess the quality of the “space/location”? What voices should participate in understanding about a particular child? How do you evaluate the intervention? (What evolution? Of the characteristic behaviors of ASD? Of the learnings linked to the common curriculum? Of the functional curriculum?) This means adequate curriculum taking into account the heterogeneity of ASD. Which curriculum(s) to choose? General, considering the national curriculum? Adapted? Focused on the specifics of ASD? How the contents should be worked taking into account the places, strategies, behaviors of the child? Given the objectives of working on the involvement of the team, who does what? How, when, where is the development? What evidence to consider? What needs, what priorities, what team? How is generalization promoted, in what contexts? How to promote adequacy? Who is responsible for developing, determining, achieving, transforming locations, practices?
5. Quality of life (Moons, Budts, De Geest 2006; Correia 2013a; Theofilou 2013). Articulating the difficulty in defining, in a consensual way, the concept of quality of life, the Theofilou proposal was considered in this study. To this author, quality of life includes areas such as “family, work, free time, health, finances, self-esteem, feelings of belonging, relationships with others, personal fulfillment” (Theofilou 2013, p. 2). In this intersection between the different voices heard in this investigation and the theory we can analyse the specific approaches/programs by asking such questions as: 1. Family: What space/time/listening is given to the family to talk about their needs, their choices? 2. Services: How is the articulation between services, contexts, specific approaches processed? How is a family supported financially and has to support an approach that is not agreed by existing legislation?

The main objective of this research was to contribute to a broader view of the different dimensions that should be considered when choosing a specific intervention approach for students with ASD and, at the same time, to contribute to a reflection on teacher training involved in daily intervention with students with ASD.

The questioning that was being reconstructed throughout this investigation allowed us to outline a series of dimensions that should be placed when establishing an intervention with children with ASD. The voices heard in this narrative are those of the people who deal with the unpredictability of students, children, the reactions of society, and who with their availability have helped to clarify essential aspects to be taken into account. The intervention with children with ASD, this has been mentioned by many of the actors, has to have a renewed look because it is one of the most important problems in the life of families and on inclusion in society and only in collaboration (services, family, society) it is possible to find better solutions for the daily care of these students (Baron-Cohen 2009; Correia 2013a, 2013b).

Although there is no single program to be used with people with ASD (National Autism Center 2009, 2011; Charman et al. 2011; Koegel et al. 2011). An appropriate intervention must respect the individual needs of each child with ASD and their families.

As a recommendation, we consider essential to cross-reference the current investigations on specific interventions for people with ASD with the curricula of initial, continuous and in-service training of teachers and verify, from the interpretation of the concept of inclusion given by the Salamanca Declaration (1994) and ratified by most of the European states as mirroring pedagogical practices in the daily lives of schools.

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