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PSYCHOLOGICAL REASONS AND ETHICAL ISSUES RELATED TO EARLY DIAGNOSIS AND INTERVENTION IN CHILDREN WITH AUTISM SPECTRUM DISORDERS

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REZUMAT. Raţiuni psihologice şi probleme etice cu privire la diagnosticul şi intervenţia în cazul copiilor cu Autism. În ultima decadă, incidenţa cazurilor de autism a crescut, la nivel mondial, la valori foarte ridicate. Totuşi, acest traiect accelerat nu poate fi cauzat doar de creşterea numărului de persoane care suferă de autism, ci poate fi atribuit şi altor factori. Această lucrare prezintă problematica creşterii ratelor de autism şi oferă o scurtă descriere a semnelor timpurii din primul şi al doilea an de viaţă. Intervenţia comportamentală timpurie este prezentă ca fiind o metodă eficientă de intervenţie pentru copiii care prezintă această tulburare. Câteva aspecte etice şi psihologice sunt menţionate pentru a sublinia importanţa şi necesitatea intervenţiei timpurii.

Cuvinte cheie: *tulburări din spectrul autist, diagnostic timpuriu, intervenție timpurie, etica.*

ABSTRACT. In the past few years, the reported incidence of autism has increased at a remarkably high rate across the world. However, this accelerating trend may not be due to an actual increase in the number of people who exhibit behaviors characteristic of autism, but may be attributed to other factors. This paper presents the problematic of the increased rates in Autism Spectrum Disorders and offers a brief description of early signs during the first and second years of life. The early intensive behavioral intervention is presented as being an effective method for young children with Autism Spectrum Disorders. Some psychological and ethical aspects are presented in order to point the importance and the necessity of early intervention.

Keywords**:** *autism spectrum disorders, early diagnosis, early intervention*, *ethics.*

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1. INTRODUCTION

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM, 5th Edition), the diagnostic criteria for the autism spectrum disorder include: a) persistent deficits in social communication and social interaction across multiple contexts and b) restricted, repetitive patterns of behavior, interests, or activities. The heterogeneity of the spectrum involves the severity of the condition, developmental level, chronological age, and associated conditions (mental retardation, language impairment) and challenging behaviors.

This heterogeneity constitutes a challenge for the development of a comprehensive early detection strategy. Nevertheless, it is essential to develop effective approaches to identify and diagnose children with ASD as early in life as possible. Early identification and diagnosis help reduce the confusion about the diagnostic and strange behaviors, the level of distress among parents who do not understand the reasons for their child's behavior; the early diagnostic leads to early intervention programs aimed at helping children modify their behavior and for parents to learn new skills.

In the last decade there has been a growing interest in ASD due to increased number of reported cases of autism at a very high rate across the world (Hertz-Picciotto & Delwiche, 2009; Nygren et al, 2012; Baxter et al, 2015). In a literature review published by Matson and Kozlowski (2011) the authors presented studies aimed at identifying the frequency of ASD in general population and concluded that the numbers are increasing rapidly and in a relatively few number of years.

The *World Health Organization* (*WHO*) reported, at the beginning of 2016, that 1 in 160 children has an ASD and could be higher, as reported by well-controlled studies (although autism prevalence in many countries remains largely unknown). Also, *Centers for Disease Control and Prevention (CDC)* published combining data for a period of twelve years, presented in *Table 1*.

Table 1. Prevalence of ASD (2000-2012) Combining data provided by Centers for Disease Control and Prevention (https://www.cdc.gov/ncbddd/autism/data.html)

Surveillance year	Birth year	Number of ADDM Sites reporting	Prevalence per 1000 children (range)	This is about 1 in X children …
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3.-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 120
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.6 (8.2-24.6)	1 in 68

This growing prevalence is alarming and researchers have focused on finding the possible causes However, this accelerating trend may not be due to an actual increase in the number of people who exhibit behaviors characteristic of autism, but may be attributed to differences of, or changes in: eligibility criteria, subjective judgments in the assessment process, non-response bias, changes in service availability, varied case finding methods, the diagnosis of very young children, accuracy of diagnosis, cultural practices, more knowledge of the parameters and awareness of autism, better trained clinicians, and possibly false-positives diagnoses (Posserud et al, 2010; Baxter et al, 2015; Eriksson et al, 2013). Moreover, accurate prevalence rates of autism are challenging to achieve, as autism can occur along with other disabilities (Kopetz & Endowed, 2012).

Calculating prevalence is often the first step toward launching government and nonprofit mental health services. Numbers can also lead to scientific insights on the genetic, environmental and cultural underpinnings of autism. Researchers continue their work in order to learn more about the condition's etiology, its impact on families and on national economies, methods to accommodate demonstrated behavioral concerns and approaches that can best inform the public and teachers who assist individuals affected by autism.

The increase in ASDs has important public health and policy implications, particularly given that most people living with ASDs today are adults and this will continue to be the case (Baxter et al, 2015).

2. EARLY SIGNS OF ASD

The worldwide concern for the increase of ASDs determined researchers and practitioners to focus on early diagnosis and intervention. Although ASD is increasingly thought of as having a genetic basis (Sokol & Lahiri, 2011; El-Fishawy & State, 2010), there are no biological markers for it. Also, despite the fact that there is a growing number of instruments used for diagnosing and documenting autistic symptoms, to date the "gold standard" (Volkmar, 2005) in diagnosis is clinical judgment based on behavioral manifestations.

Usually, ASD is diagnosed around 3 years old or even later (Fountain et al, 2011; Jo et al, 2015). According to Watson et al (2003) symptoms include (taking into account several domains): *affective development* (limitations in facial expression, fewer facial expressions, ambiguous facial expressions, a lack of social smiling), *sensory processing, attention, and self-regulation* (hypersensitivities to sound, aversion to social touch, avoidance of certain food textures, lack of response to pain, poor orientation to visual stimuli, and over focused attention or preoccupations with various sensory features of objects), *praxis and imitation* (imitation deficits, difficulty forming internal representations of visually modeled

actions), *communication* (impaired key aspects of nonverbal behavior that typically support the mapping of language onto real world objects and relations, less babbling and gesturing during early development, limited range of preverbal communicative intentions), *play* (less proximity to peers, reduced levels of social initiations, fewer responses to social overtures, and more solitary activities), and *motor features and stereotyped/repetitive behaviors* (lags in gross motor development, unusual postures, clumsiness, and motor planning problems).

Given that some of the primary symptoms of autism may not manifest themselves unequivocally before the age of 3, it is interesting that a number of researchers are convinced that a meaningful diagnosis can be made in children younger than 12 months, on specific areas such as *movement*, *social behaviors*, *attention*, *communication*, *orientation/response to name* and *paradoxical reactions to sounds and/or semblance of deafness* (Lemke et al, 2013; Zwaigenbaum et al, 2013; Hutman et al, 2012; Guinchat et al, 2012).

Although significant progress has been made in the direction of identifying ASD as soon as possible, a clear diagnostic in the first year of life might prove difficult in terms of reliability. The signs become increasingly evident with increasing age and might not be fully manifest until later in life, particularly in children who have IQ and language skills within the normal range. Ethical aspects are important due to the fact that some vulnerable population are presenting higher risks to delay the time of diagnostic. Among them we pointed ethnicity and migrants as important factors (Valicenti-McDermott et al, 2012).

Chawarska et al. (2007) found evidence for short-term stability of the autism diagnosis assigned in the second year of life, while the study of Kleinman et al. (2008) indicate diagnostic stability at acceptable levels at age 2. Studies aimed at identifying symptoms of ASD in the second year of life help to further clarify patterns of early indicators as they become more pronounced.

In a study of Wetherby et al. (2004) were identified nine red flags for ASD:

- lack of appropriate gaze,
- lack of warm, joyful expressions with gaze,
- lack of sharing enjoyment or interest,
- lack of response to name,
- lack of coordination of gaze, facial expression, gesture, and sound,
- lack of showing,
- unusual prosody,
- repetitive movements or posturing of body, arms, hands, or fingers,
- repetitive movements with objects.

Chawarska et al. (2007) identified a series of symptoms specific for children with autism in the second year that overlap on those found by Wetherby et al. (2004), but they also include limited response to joint attention bids and

delays in functional and symbolic play. Severl years after this study, Landa, et al (2007) found that children classified as having an early ASD diagnosis (14 months) showed abnormalities in joint attention (similar to Chawarska et al.), in initiation of communication with others, and in the variety of vocal and nonvocal forms used to express communicative initiations by 14 months of age, and that these abnormalities persisted through 24 months of age.

Some other studies pointed that children usually failing on three key elements (proto-declarative pointing, gaze-monitoring, and pretend play) are at risk of receiving a diagnosis of autism at 18, respectively 24 months (Robins et al, 2001; Baron-Cohen, 1992). Zwaigenbaum et al. (2009) warn us that, although there have been significant advances in our ability to detect early signs of ASDs, diagnostic evaluation in children younger than the age of 2 remains challenging.

Matson et al (2008) note that early diagnosis is a good development only if the diagnoses are reliable, have good predictive validity, and prove useful in assisting in better care and prognosis. Development of specific approaches to infants and very young children is an important research priority and is essential in understanding the boundaries of the disorder in relation to broader autism spectrum conditions.

3. THE IMPORTANCE OF EARLY INTENSIVE BEHAVIORAL INTERVENTIONS (EIBI) AND TO PROVIDE EQUAL CHANCES TO HEALTH AND EDUCATIONAL SERVICES

There is general consensus that ASDs should be identified as early in life as possible, with a view to ensuring that intervention can start as quickly as possible (Fernell et al, 2013). Due to the fact that more children under the age of 3 years are being diagnosed with ASD, early interventionists face the challenge of identifying appropriate programs to meet the unique needs of very young children with ASD and their families. The increased numbers and the earlier age at diagnosis are having a dramatic impact on early intervention providers. Any child would benefit from appropriate early interventions building on her or his behavioral strengths and remedying any weaknesses (Poling & Edwards, 2014). As such, early diagnosis and information are needed in order that an autism friendly environment be “created” around affected individuals (Fernell et al, 2013).

Roberts and Prior (2006), reviewing the international literature in order to provide guidelines for best practice for early intervention programs for children with ASDs, stress the following key elements:

1. provide an autism specific curriculum content focusing on attention, compliance, imitation, language, and social skills,

2. address children's need for highly supportive teaching environments,
3. include specific strategies to promote generalization of new skills,
4. address children's need for predictability and routine,
5. adopt a functional communication approach in addressing challenging behaviours,
6. support children in their transition from the preschool classroom,
7. ensure that family members are supported and engaged in a collaborative partnership with professionals involved in the delivery of treatments.

As we improve our ability to identify toddlers with ASDs, the need for research on the efficacy of very early intervention approaches becomes critical. There is strong evidence that early intensive behavioral intervention (EIBI) programs are effective in changing the natural long-term outcome for many individuals with an early diagnosis of autism (Estes et al, 2015; Nah et al, 2014).

The core elements of EIBI involve (Reichow et al, 2014):

1. a specific teaching procedure referred to as discrete trial training,
2. the use of a 1:1 adult-to-child ratio in the early stages of the treatment
3. the implementation in either home or school settings for a range of 20 to 40 hours per week across one to four years of the child's life.

Lovaas (1987) suggested that 47% of the autistic children included in his study achieved normal intellectual and educational functioning and maintained these gains when assessed at 7-year follow-up. Adapting this model proposed by Lovaas, several studies proved that there is an improvement in the adaptive behavior, increases for IQ scores and outperformance for visual-spatial skills, language, and academics (Eikeseth et al, 2012; Howard et al, 2005). Other studies using EIBI in other formats than Lovaas suggest higher adaptive functioning and higher cognitive skills, improvements in language, daily living skills, and positive social behavior (Flanagan et al, 2012; Remington et al, 2007).

Matson et al (2012) conclude that studies on EIBI routinely demonstrate good or superior effectiveness and positive effects. The results consistently showed that children with autism improve significantly with early intervention. These improvements are stable over the years. The findings highlight the importance of ensuring that children begin intensive therapy as soon as possible after the diagnostic.

Early intervention is very important for the future development of a child with ASD. Strategies adapted to each case may increase the rate of developing skills in order to diminish the negative aspects related to the problem. On the other hand, early intervention will help parents to cope with stress determined by the child's behavior and they will be more skillful to interact and to communicate with their child.

Ethical aspects must not be ignored when it is about a vulnerable population: children in need. They must be assisted with dignity and to provide

equal chances to health services, with no ethical, racial, economical, religious, ethnical or educational reasons. Seventy-five of approximately 120 countries in which an ASD-specific organization has been established are low or middle income (Daley et al, 2013). Many ethical dilemmas were preferring to the aspects of developing studies or the level of literacy of the investigated population or understanding the informed consent in case of parents with a low level of education.

Also, due to the fact that low or income countries are presenting a high number of cases of children with ASD, an international strategy must be adopted in order to provide equal chances for children living in poor countries to access health and educational services.

4. CONCLUSIONS

As worldwide awareness of autism gains momentum, there is a need for research advances from more countries. Continued international research in assessment and treatment may help extend work from older and more able individuals to the first years, if not the first months, of life. Psychological aspects and ethical reasons must be considered due to the fact that religion, ethnicity, migration or parents level of education represent important factors for a proper diagnostic and an early intervention.

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