

Education of children with autism

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Abstract

This article offers information about the education of children with autism. This is a social-education problem that is important in Romania. This article touches on topics such as the definition, evolution and causes of this problem, the social and educational implications, the intervention strategies and measures to combat the social educational problem. Autism can affect learning and behaviour in the classroom, but not only this. Autism can affect the social life of a child and more importantly the way he will cope in life because it can be hard for people with autism to maintain a job or socialize. TSAs can significantly limit a person's ability to engage in daily activities and participate in society. They negatively influence a person's social and educational achievements, as well as employment opportunities. An autistic child does not establish eye contact, does not allow to be taken in arms, has no fear in the face of danger, lacks inhibition in general behaviour and extreme anxiety. He can also have a delay in mental development and rigidity in thinking and action.

Keywords: autism, TSA, education, children, Romania;

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1. Introduction

In the DSM-IV (Handbook of Diagnosis and Statistics of Mental Disorders), autism is classified in the category of “pervasive developmental disorders”, between “mental deficiency” and “specific developmental disorders”.

The education of children with autism is a very important part of the education system because every child deserves to receive a good education. Autistic children have difficulties in social interaction and in communication. They have hyper or hypo reactivity to sensory stimuli or unusual interest in sensory aspects of the environment. Their entire education is based on special educational requirements.

2. The analysis of the social-educational problem

2.1. Defining the social-educational problem

Autism Spectrum Disorders (ASD) are a group of complex brain development disorders. "This umbrella term covers: autistic disorder, Asperger's disorder and atypical autism.

These disorders are characterized by difficulties in interaction and social communication and by a limited range of interests and activities, with a repetitive character” (National Romanian Centre for Health Assessment and Promotion, 2019, p. 2).

Autism is, in part, an inherited developmental disorder that involves early macroscopic growth of the brain in most cases and dysfunction that affects multiple cortical and subcortical regions that mediate autistic symptoms, including prefrontal and temporal cortices (Stoner, Chow, Boyle, Sunkin, Mouton et al, 2014).

2.2. Evolution of the social-educational problem (incidence, prevalence / distribution at social level, social map, demographic, regional map, etc.)

A study titled Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic

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analysis for the Global Burden of Disease Study was published online in 2018 and conducted by several collaborators of global research on developmental disabilities such as Olusanya, BO, Davis, AC, Wertlieb, D., Boo, NY, Nair, MKC, Halpern, R., & Halfon, N. This study shows that the overall burden of developmental disabilities has not significantly improved since 1990, suggesting inadequate global attention to the developmental potential of children who survived childhood as a result of child survival programs, especially in sub-Saharan Africa and South Asia.

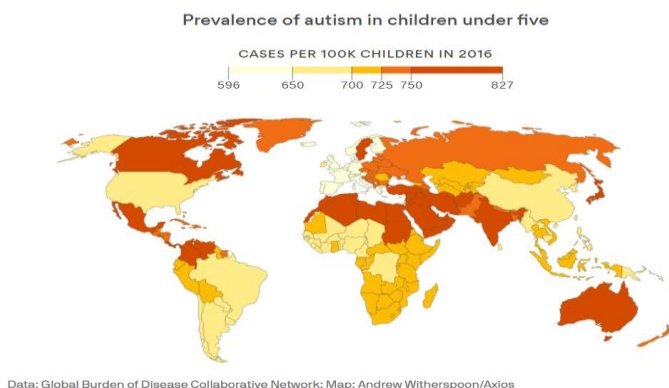


Figure 1 – Global prevalence per 100,000 inhabitants of autism in children under five in 2016

Figure 1 shows that Romania has a prevalence of autism in children under five in 2016 between 700 and 725. According to the legend of the map, TSA was the least widespread in Western Europe, and Romania's prevalence is in the middle.

The ASDEU project (Autism Spectrum Disorders in the European Union), a pilot project funded by the European Parliament and led by the European Commission, conducted a research between 2015-2018 aimed at evaluating various research tools and methods to measure the prevalence of ASD (disorders of the autism spectrum) in the EU.

ASDEU tested three methods to estimate the prevalence of ASD (National Health Assessment and Promotion Centre, 2019, p. 4):

1) two-phase screening - teachers who nominated children through a form, then through a questionnaire applied to parents

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2) one-phase screening by administering questionnaires to parents

3) analysis of data from national registers.

The three methods were tested in 23 regions in 12 European countries. A total of 631,619 children were involved in this research.

Some key findings were:

- Prevalence studies using data obtained from school questionnaires: in Vienna, the researchers found that the response rate was 19.3% "lower than expected". This was partly due to the acts that schools had to carry out to meet ethical requirements. Many schools felt that participation "represented too much effort" and reported that parents' motivation to participate in this study was low. This type of problem regarding the accessibility of research has also been identified in Bulgaria and Italy (Posada de la Paz, 2018, p. 1). Romania received a response rate of 100% (out of 122 schools - a random sample of the total). This was attributed to the strong links that researchers had with the Romanian Ministry of Education and the collaboration of schools (ibidem).

2.3. Causes of the social-educational problem

The causes of autism are still unclear. There are numerous studies on this issue.

In 2014, the New England Journal of Medicine published an article based on a study by a team of researchers from the Universities of California, the Sand Diego School of Medicine and the Allen Institute for Brain Science in Seattle. The conclusion of the study was the following: "the brain is affected only in the form of" patches "in the cortical layers, patches present especially on the frontal and temporal lobes" (National Health Assessment and Promotion Centre, 2019, p. 13).

The researchers identified discrete spots of disorganized cortex in most post-mortem samples obtained from young children with autism that they examined. These patches have occurred in regions that mediate functions that are disrupted in autism: social, emotional, communication, and language functions. Such abnormalities may represent a common set of developmental neuropathological features that underlie autism and likely result from layer formation irregularity and layer-specific neuronal

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differentiation in the stages of prenatal development (Stoner, Chow, Boyle, Sunkin, Mouton et al, 2014).

Another research study (Loss of mTOR-Dependent Macroautophagy Causes Autistic-like Synaptic Pruning Deficits) conducted in 2014 by Columbia University Medical Center showed that adolescents and children with autism have an excess of synapses compared to children who develop normally. "In the study, American researchers compared the development of the brain in children and adolescents who have autism spectrum disorders with the neural networks of children who do not have these symptoms" (National Health Assessment and Promotion Centre, 2019, p. 14). Normally the number of synapses is halved during development, but in autistic people the number of synapses decreased by only 16% (ibidem).

The education of children with autism is a socio-educational problem because they present (Cucoş, 2009, p. 613-614): communication and language difficulties; the inability to develop a normal attachment and the existence of unusual ways to respond to environmental stimuli; the inability to make eye contact; does not allow to be taken in arms; the absence of fear in the face of danger; does not identify himself; lack of inhibition in general behavior; extreme anxiety; delay in mental development; rigidity in thinking and action.

2.4. Social and educational implications of the problem

TSA's can significantly limit a person's ability to engage in daily activities and participate in society. They negatively influence a person's social and educational achievements, as well as employment opportunities. While some individuals with ASD can live independently, others have severe disabilities and need lifelong care and support.

Autism spectrum disorders often impose a significant emotional and economic burden on people with these disorders and their families. Caring for children with a severe form of the condition can be demanding, especially if access to services and assistance is inadequate. Therefore, caregiver empowerment is increasingly recognized as a critical component of caring for children with ASD.

In Romania, a study on the service needs of parents of children and young people with ASD was developed in 2015 by the Sociometrics

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Association. According to this research report, “from the perspective of access to therapy services for children with ASD, 68% of children receive interventions in a single institution, while 32% access services in several institutions” (Toth & Mareş, 2015, p. 7). But the problem identified is that "most children follow up to 10 hours of therapy / month, ie about 2-3 hours / week, given that international recommendations are 25 to 40 hours of therapy per week" (ibidem). In terms of education, the study found that if a child with ASD had a companion at school, he or she would benefit from a much better development. "Only 17% of children who are included in a form of schooling benefit from the shadow / companion, and half of the parents of those who do not benefit from this service are convinced that the presence of the companion would be very important for the child's progress" (Toth & Mareş, 2015, p. 8).

The research report concludes that Romania is not yet fully prepared to provide adequate conditions for children with autism and their families.

3. Measures to combat the educational social problem

The measures to combat the social-educational problem are global, European, national and local.

As for the European measures, there are agreements, declarations, programs, projects for the problem of education for children with autism. In September 2015, the European Parliament adopted a written Declaration on Autism, co-signed by 418 Members of the European Parliament.

There was a book published in 2015 called *Protecting the rights of people with autism in the field of education and employment - International and European perspectives*. This report provides an in-depth analysis of legislation and practices related to education and employment for people with autism in EU Member States. Autism-Europe, together with four other partners, is involved in the project entitled *Vocational training in communication and teaching approaches in autism spectrum disorders (TSA)*, which aims to empower teachers in Greece, Romania and Belgium to address

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effective and alternative teaching and communication methods for children with ASD. Carried out from October 2018 to September 2020, the project was funded by the European Commission's Erasmus + Program.

The ChildIN project, a new Erasmus + project, aimed to develop a training program for people caring for children with ASD, aiming to include these children. The ChildIN project provided training on autism in European children. It took place from November 2018 to December 2020. Autism Spectrum Disorders in the European Union (ASDEU) is a pilot project funded by the European Parliament and administered by the European Commission since 2018. EU Project: ASD-EAST - Autism Spectrum Disorder - Empowering and Supporting Teachers (2018-2020) focuses on empowering specialist educators in the Central / Eastern / Balkan environment to support the effective inclusion of children with autism spectrum in education. Carried out from September 2018 to August 2020, the project was funded by the European Commission's Erasmus + Program. EU Project: ETTECEC- Together we grow (2017-2019). This two-year Erasmus + project has developed and implemented an innovative pedagogical approach based on the paradigm of inclusive education, by developing an online teaching course focused on children aged 0-6 (preschool).

Meanwhile, Romania has a lot of national measures, most of them being laws and projects funded by NGOs:

- LAW no. 487 of July 11, 2002 on mental health and the protection of people with mental disorders;
- ORDER no. 18 of February 26, 2003 regarding the approval of the Methodological Guide for the evaluation of children with disabilities and classification in a degree of disability;
- DECISION no. 1251 of 13 October 2005 regarding measures to improve the learning, training, compensation, recovery and special protection of children / pupils / young people with special educational needs in the special education and special integrated education system;

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- LAW no. 448 of December 6, 2006 regarding the protection and promotion of the rights of disabled people
- LAW no. 151 of July 12, 2010 regarding specialized integrated health, education and social services for people with autism spectrum disorders and associated mental health disorders;
- METHODOLOGY of October 7, 2011 about the organization of educational support services for children, pupils and young people with special educational needs integrated in mainstream education;
- ORDER No. 5573 of October 7, 2011 regarding the approval of the Regulation of organization and functioning of special education and special integrated education;
- LAW no. 197 of November 1, 2012 on the quality assurance in the field of social services;
- NORM of April 15, 2016 ON THE APPLICATION of the Law on mental health and protection of people with mental disorders no. 487/2002;
- METHODOLOGICAL NORMS from August 25, 2016 for the application of Law no. 151/2010 regarding specialized integrated health, education and social services for people with autism spectrum disorders and associated mental health disorders.

The National Institutions responsible for intervention, prevention and combating social and educational problems are: Ministry of Education and Research, Ministry of Health, National Authority for Child Protection, General Directorate of Social Assistance and Child Protection, Public Social Assistance Service, National Council for Combating Discrimination. Nationally, an NGO called HELP AUTISM has created "RO TSA" that represents, at national level, a coalition of 60 non-governmental organizations, active in the system of providing integrated and personalized services (social, educational and health) addressed to children with ASD and their families. The network benefits from the support of 67 public institutions (CSIs, DGASPCs, CJRAEs) whose representatives participate in the activity of the working groups.

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Locally, in our town, the NGOs were very active. For example, The Social Assistance Department of Târgoviște City Hall in partnership with the Help Autism Association inaugurated in 2015 the Day Center for children with autism and Down syndrome "Sfânta Maria" - the first center that offers social and psychological services (therapy) for children with Autism Spectrum Disorders and Down Syndrome in Targoviste and Dambovita county (Help Autism, 2015).

4. Intervention strategies: attributions and responsibilities

4.1. The role of specialists (the role of multidisciplinary teams)

According to the Methodological Norms for the application of Law no. 151/2010 on specialized integrated health, education and social services for people with autism spectrum disorders and associated mental health disorders from 25.08.2016, a multidisciplinary team:

- consists of all teachers who work with the child, depending on its type.
- is organized at the level of each educational unit in which children with autism spectrum disorders and associated mental health disorders are educated, in order to coordinate interventions in the direction of achieving the proposed objectives.
- meets monthly or as often as needed, outside of class hours / teaching or therapeutic activity, and conducts interim evaluations of the student's progress during the application of the personalized intervention plan.
- makes a concise written report on the status and results of the application of the personalized intervention program that will be presented to the internal commission for continuous evaluation and to the parents / legal representative.

Article no. 33 of the Methodological Norms for the application of Law no. 151/2010 is the one that explains the composition of the multidisciplinary team regarding the education service of children with ASD:

“(2) At the level of the special education unit, the multidisciplinary team consists of all teachers who interact with the student (special psychopedagogy teacher, psychopedagogue teacher,

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psychodiagnostic teacher, teacher-educator, other teachers), social worker and doctor or assistant from the school medical office, as appropriate.

(3) At the level of the mass education unit, the multidisciplinary team consists of the itinerant and support teacher, the counsellor from the district psycho-pedagogical assistance office, the speech therapist from the district inter-school speech therapy office, the main teacher of the class in which the student is enrolled and the doctor or nurse from the school medical office, as the case may be.”

4.2. The role of civil society

Representatives of civil society, non-governmental organizations, research institutes, etc., have a significant contribution to autism.

NGOs actively participate by piloting specialized promotion, prevention and intervention services and in the in-service training of autism specialists. They developed therapy programs, trained therapists to help children with autism recover and teachers to facilitate the adaptation of children with autism in schools. Also, they developed awareness programs to prepare society to accept and integrate them.

For example, in 2018, according to the annual report published by the Help Autism Association, they:

- supported 500 children in recovery programs;
- funded 220,000 hours of therapy;
- trained 66 psychologists through the ABA Therapy Training Program and Austerity Practice course;
- 500 children were helped to be evaluated through the National Diagnosis and Evaluation Program.

4.3. The role of responsible institutions

The National Authority for the Protection of the Rights of the Child and Adoption, the General Directorate of Social Assistance and Child Protection (DGASPC), the Public Social Assistance Service and the National Council for Combating Discrimination have the role:

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- to promote the rights of the child and the rights of persons with disabilities;
- to monitor the observance of the rights of the child by centralizing information at the national level on the principles and norms established by the United Nations Conventions on the Rights of the Child and the Rights of Persons with Disabilities
- to ensure control, coordination and methodological guidance regarding the application of legislation in the field of protection and promotion of children's rights.

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