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Macedonia and Autism

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Historical Background

The Republic of Macedonia has gone through a long and painful process of transition during last 25 years. The cumulative effect of the transitional recession and the socially stressful process of transition have most seriously affected marginalized groups, such as persons with autism spectrum

disorders being among the most vulnerable (Trajkovski 2008).

Autism in Macedonia has a short history. It is not like the history of autism in the USA or other western developed countries. For many decades, especially during the communist period of Yugoslavia, children with autism were diagnosed as mentally retarded, schizophrenic, or some other diagnosis. Children and adults with autism missed regular treatment because of inadequate institutions, lack of finances, parental ignorance, and prejudices in the society. Many of the children with autism have been placed into big institutions such as the Special Institute in Demir Kapija. Because of the poor economic situation, low standard and inappropriate services of social assistance; families were no longer able to care for the medical, physical, and psychological needs of their children and found institutions to be some alternative. Macedonia also has a history of reporting fewer cases of ASD than can reasonably be assumed to exist nationally, indicating the probable existence of cultural biases or other errors in diagnosis (Trajkovski et al. 2005). So, there are no reliable data about the statistics on how many children with ASD are diagnosed. A National Register of persons with ASD is not established yet.

The first case study about child with autism was described more than three decades ago (Kopachev and Nastov 1983). Then, after 13 years without any activities from the governmental or nongovernmental sector, the first parent

association was established in 1996. The Society started its activities and was very productive for 2 years. Children were included for treatment in special schools and institutions for rehabilitation in Skopje. Due to a lack of interest, the society stopped its activities in 1998 (Ajdinski 2005). The author of this entry started with the first doctoral thesis about autism entitled: "Immunogenetic analyses in persons with autism in Republic of Macedonia" in November 1999. Following the research and treatment of autism in the world, the Institute for Special Education and Rehabilitation at the Faculty of Philosophy and the Institute for Immunobiology and Human Genetics at the Faculty of Medicine took the initiative and the Macedonian Scientific Society for Autism (MSSA) was established as an NGO in May 2000. MSSA directed its work towards: primary prevention of people with autism, research on the mechanisms referring to autism, research on the effects of rehabilitation of people with autism, treatment of people with autism, as well as coordination with both governmental and non-governmental organizations and cooperation with international organizations dealing with autism. In a very short time, the NGO established the number and presented a survey of families with autistic people and started to prepare the National register, introduced two web sites on the Internet (Autism-Macedonia and a web site of the association), became a member organization of Autism Europe, and published a brochure about people with autism. Its members started to participate in scientific projects, attending at conferences in the country and abroad, and had presentations on TV and radio broadcasting. Their professional and scientific works were published in scientific journals.

There is a lack of knowledge on ASD among professionals who are involved in work with children with ASD, a lack of standardized protocols for early detection, diagnosis, and assessment tools. The precarious use of international classifications and diagnostic tools are resulting in low and late detection of autism. Officially in Macedonia, the ICD-10 diagnostic manual is still used in the health care system (ICD, 1992).

In spite of our lobbying activities during last 17 years, there is still no national strategy about autism spectrum disorders in the country.

Legal Issues, Mandates for Service

Article 39 from the Constitution of the Macedonia guarantees that every citizen has the right to health care. Citizens have the right and the duty to protect and promote their own health and the health of others. Article 44 grants the right to education for every citizen. Education is accessible to everyone under equal conditions. Primary education is compulsory and free of charge. According to the Law for elementary education, special educational plans and curriculum are required to nurture and educate pupils with special educational needs.

The Macedonian constitution does guarantee access to health care to its citizens, but local health care providers are not adequately equipped to serve individuals with autism spectrum disorders. Among other issues, there is limited neonatal screening for genetic disorders, the nation lacks a centralized database on disabilities, and the quality of health care in urban centers does not extend to rural areas. Macedonian schools do not have appropriate staff to work with children with autism according the research conducted by the state attorney office in schools in several towns in Macedonia. It showed 93 children with ASD are going to 109 primary schools. The data analyzed by the state attorney office show that only a small number of the schools have a completely professional team which would work with autistic children. Of all 109 schools covered in the survey, only 39% have a professional team comprised of a teacher, a psychologist, a pedagogue, and a special education teacher. On the other hand, 28% of the schools have no staff whatsoever to work with children with ASD, nor have the parents hired at their own expense a special education teacher who would work with those children (www.independent.mk).

Social institutions on the local level are not capable of ensuring that people with autism can remain in their area of residence and be provided

with adequate educational and social services. The lack of statistical data on people with a disability hampers an evaluation of whether all persons with any given disability are socially jeopardized and if they are able to access their rights in the field of social care. The Law on social protection established measures and services in the field of social protection and care through social prevention, de-institutional care, and protection and the right for social support (Trajkovski 2008).

The Republic of Macedonia ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol on 29 December 2011 and it is a step forward in improving the quality of life of people with ASD in Macedonia. The diagnosis of autism or other developmental disabilities does not entitle the individuals or their families to benefits – they have to apply for the disability status.

Overview of Current Treatments and Centers

In the Republic of Macedonia, there is no systematic approach to early intervention services and programs. There are no service providers for the early intervention of children with ASD. Home-based interventions and other social services available in Western Europe and the United States are relatively limited (Trajkovski 2010). Parents access various kinds of treatments for their children, the most popular are training of social skills, psychomotor re-education, biomedical treatment, and treatment with medicaments. Sometimes they use unproven treatments which can be dangerous for the health. The use of ABA and TEACCH is at an incidental level. Macedonian pediatricians, psychologists, and rehabilitators lack the skills to conduct such early kinds of treatments. There is no effective law in Republic of Macedonia for early intervention practices (Trajkovski and Jurtoski 2016).

According to the Constitution of the Republic of Macedonia, the concept of freedom and rights is embedded in a citizen-liberal democratic concept, which begins with the principle of

citizenship. An essential citizenship freedom and right is personal freedom and the right to acquire education, from the elementary to the university level, which ensures not only personal development and the general development of the individual, but also to the ability to contribute to raising the general cultural level of the society in which they live. According to the Law for elementary education, special educational plans and the curriculum are required to nurture and educate pupils with special educational needs. The regional boards of psychology, medicine, and education give recommendations about the conditions which would best serve the child, but the parents are not legally bound to follow them, and they can enroll the child into a school of their choice. Also for education in schools, there is no legislation to guide and support parents into choosing the type of school to send their children to. Great numbers of parents send their children to mainstream schools with a 1:1 specialist assistant who is financed by the parents. Having a child with autism spectrum disorders in Macedonia can have a huge financial impact for the family. It appears that policy makers are not interested in this area and have no understanding of the problems families face who take care of children with autism. Authorities have to start with certificated programs for training the professionals. Almost half of parents are not satisfied with early intervention programs in our country. One third of parents spend between 250 and 350 euros on early treatment which is a significant amount of their own budget (Trajkovski and Jurtoski 2016). Some of children with ASD stay at their homes out of the system of special or general education. There are no statistics on this issue.

In last 2 years, the Ministry of Labor and Social Policy opened two daily care centers for children with ASD in two towns: Skopje and Shtip. In the last 5 years, three more parental associations were created in Skopje, Shtip, and Bitola, but they have quite low impact in the field due to lack of money and lack of knowledge.

The condition of adult people with ASD is very bad. Nobody takes care of them. They do not have access to complementary treatment approaches. Many individuals with ASD who do not receive

enough support from their families, especially adults, are institutionalized into neuropsychiatric institutions.

Overview of Research Directions

The first publication about autism from Macedonia in a scientific impact factor journal appeared in 2004 (Trajkovski et al. 2004). Two scientific and clinical handbooks such as *Autism* (Trajkovski 2004) and *Autism and Pervasive Developmental Disorders* (Trajkovski 2011) and some articles are published in Macedonian language and because of that not readily available for international audience (<http://www.mssa.org.mk>). Also, there are a significant number of publications in international peer-reviewed journals, such as those dedicated to the plasma concentration of food-specific antibodies in children with autism (Trajkovski et al. 2008), family analysis of immunoglobulin classes and subclasses in children with autism (Spiroski et al. 2009), and immunogenetics and autism (Trajkovski and Spiroski 2015). Some other research groups have published more socially oriented research, such as sexual development, sexual behavior and gender identity of persons with autism (Mladenovska and Trajkovski 2010), employment of people with autism (Stankova and Trajkovski 2010), stress, coping and support among parents of children with autism (Nolcheva and Trajkovski 2015).

Overview of Training

Only physicians (psychiatrists and pediatricians) are allowed to diagnose autism officially. A wider range of specialists provide educational and rehabilitation services. On the initiative of the writer of this article, the Institute of Special Education and Rehabilitation at the Faculty of Philosophy introduced the subject of Autism into the curriculum of postgraduate studies in 2004 and the subject of Pervasive Developmental Disorders into the curriculum of doctoral studies in 2012 (<http://www.fzf.ukim.edu.mk>). Twelve

graduation theses, six master theses, and two doctoral dissertations were defended with autism as a main topic in last 15 years. Our University “Ss. Cyril and Methodius” trains specialists in special education and rehabilitation and speech pathologists (<http://www.ukim.edu.mk>).

The Macedonian Scientific Society for Autism provides free lectures about autism and specific approaches, such as PECS, TEACCH, and ReAttach method. The organization also participated in an EU-funded project regarding parent and professional education in conjunction with the Apollonia Foundation from Gevgelija. However, the majority of events are on an ad hoc basis and are inaccessible to most families (ESIPP project, 2015). Though parent education programs exist in parts of Europe, in others they are extremely limited or nonexistent. In 2015 the Macedonian Scientific Society for Autism started as a partner in a 3-year project (September 2015–August 2018), funded by the European Commission, in which family members, professionals, and academics from five European countries are working together in a strategic partnership to address this inequity (Belgium, Croatia, Cyprus, Macedonia, and UK). This partnership is seeking to develop a core curriculum and ecologically valid parent education materials and methods, provide parent education to families living with autism in three south-eastern European countries where previously it has been unavailable, evaluate impact using quantitative and qualitative methods, share the curriculum and materials with stakeholders, and make recommendations to decision makers (Preece et al. 2016).

Social Policy and Current Controversies

Our society is not sensitized to those persons with autism spectrum disorders. They are looked down upon, bullied, and regarded as less valuable than children with typical development. Parents hide their children with autism and do not want to expose them in public. They are ashamed of their own children and are not very eager for them to appear in electronic media. There is a huge social stigma connected to having a person

with an ASD diagnosis in the family. The authorities are not interested in helping these families. The governmental bodies do not allocate enough financial resources to this sector. In last 6 years, there have been significant changes in public awareness of autism and in social policy since MSSA started to honor international autism awareness day.

Areas of controversy focus on the role of no established treatments (especially ABA and TEACCH), in best approaches to teaching and service delivery, and issues of diagnostic practice. There is a tremendous dearth of work on adults with ASD. The authorities need to begin to see this disorder as treatable and to invest the same energy, money, and efforts into treating autism that we have put into treating cystic fibrosis, leukemia, childhood cancers, and other chronic medical disorders that affect young children.

See Also

- ▶ [Applied Behavior Analysis](#)
- ▶ [Constitution of the Republic of Macedonia](#)
- ▶ [Equity and Social Inclusion Through Positive Parenting](#)
- ▶ [Faculty of Philosophy in Skopje](#)
- ▶ [ICD-10](#)
- ▶ [Independent.mk](#)
- ▶ [Journal of Special Education and Rehabilitation](#)
- ▶ [Macedonian Scientific Society for Autism](#)
- ▶ [ReAttach.eu](#)
- ▶ [TEACCH](#)
- ▶ [University “Ss. Cyril and Methodius” in Skopje](#)

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