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ШЕСТИ КОНГРЕС НА ЗДРУЖЕНИЕТО НА ПЕДИЈАТРИ НА
РЕПУБЛИКА МАКЕДОНИЈА СО ИНТЕРНАЦИОНАЛНО УЧЕСТВО

КНИГА СО ТРУДОВИ



ГЕНЕРАЛЕН СПОНЗОР:


ALKALOID
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A Survey of Caregivers of Children with Autism in Republic of Macedonia

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Introduction: Autism spectrum disorders (ASD) is a group of complex lifelong neurodevelopmental disorders, characterized by difficulties in social interaction, verbal/nonverbal communication and repetitive behaviors. Statistics from the United States Centers for Disease Control and Prevention, identify one in 68 children (one in 42 boys/one in 189 girls) as having autism. The rapid growth of autism prevalence over the last few decades represents a significant health, social and economic issue.

Aim of the study: survey to investigate the needs of children with autism and the challenges and difficulties faced by them and their families in seeking and receiving care in the Republic of Macedonia.

Method: a survey was developed by Autism Speaks and the National Coordinators for autism from eight countries of the Southeast European Autism Network to address the needs and difficulties of the ASD children and their families.

Subjects: From January to August 2015, 60 primary caregivers of ASD children in Republic of Macedonia completed the survey.

Results: Parents first concerns about the children's development occurred at 20 months (± 15.23), and the average age at diagnosis was 29 months (± 9.49). The most common first concerns included poor eye contact, not responding to child's name, living in "own world" and unusual gestures/walking/posture. 81.66% of the children received combination of sensory, speech/language treatments, and medications. Treatments were typically provided by private special educators and the majority (78.57%) of parents are paying full amount for months or years. Majority of the children are attending state kindergartens (40%) and special schools (41.66%). Parents ranked obtaining ASD information mainly from the internet, professionals and other parents. Autism has caused serious financial problems for the families (in 75%) and emotional issues for the parents (in 70%). The primary challenges ranked by families include poor communicational skills (40%), difficulties in social interactions (35%), and stereotyped behaviors of the child (33.33%). Parents ranked firstly difficulties in and a need for improved health care services (72.41%), then improved educational possibilities (65%) and enhanced social care system (51.66%).

Conclusion: Autism is serious burden for the families in Republic of Macedonia. Parents and ASD children are facing financial and personal issues and would need improved services from the health, educational and social system.

Key words: autism, caregiver needs survey, Republic of Macedonia