

# NEEDS AND CHALLENGES FACING PARENTS/CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: THE SOUTHEAST EUROPEAN AUTISM NETWORK SURVEY

TATJANA ZORČEC

University Children's Hospital, Skopje, Republic of North Macedonia, contact: tzorcec@gmail.com

Received: 11.10.2019.

Accepted: 03.12.2019.

Original scientific paper

UDK 616.896-053.2:37

<https://doi.org/10.31299/hrri.55.2.3>

**Abstract:** *The Southeast European Autism Network (SEAN) was established to enhance understanding of diagnosis, needs and services for children with Autism Spectrum Disorder (ASD) and their caregivers in Southeast Europe. Toward this end, a survey was conducted in 2015/2016 with the main aim to understand the diagnostics, services and experiences of families/caregivers affected by ASD in the Southeast European region, including the Republic of Macedonia. The survey was performed using a questionnaire specially designed by the members of the SEAN network, which included the following four domains: demographic/family characteristics, index child characteristics, service encounters and parent/caregiver perceptions. In this article we present the findings from 60 parents/caregivers of children with ASD in the Republic of Macedonia. Although the average ages at first concern (20.1 months, SD 7.0) and at ASD diagnosis (35.3 months, SD 14.3) were comparable to those in US and Western European countries, important needs and challenges need to be addressed related to early diagnosis, interventions and inclusive educational practices. In this study we conducted descriptive analyses and non-parametric Spearman correlation analyses to examine whether current age of the child was associated significantly with time-to-diagnosis. We also conducted linear regression analysis and the t-test to measure the effects of diagnosis, parental education, time to diagnosis, and current age of the child on impact of the disorder and level of difficulties reported by the parents.*

**Key words:** *autism, caregiver needs survey, The Southeast European Autism Network (SEAN)*

## INTRODUCTION

Autism spectrum disorder (ASD) is a group of complex lifelong neurodevelopmental disorders, characterized by difficulties in social communication and interaction and stereotyped behaviours. Statistics from the United States Centers for Disease Control and Prevention identify one in 59 children as having ASD (Centers for Disease Control and Prevention, 2018); prevalence is 1% in the United Kingdom (Brugha, McManus, Bankart, et al. (2011) and even higher, from 1.81% to 2.6%, in some Asian countries (Kim, Leventhal, Koh, et al. (2011). The rapid growth of ASD prevalence over the last few decades is a significant health, social and economic issue (Baxter et al., 2015; Elsabbagh et al., 2012). No specific biological markers for ASD have been reported, so this condition continues to be defined by its behavioral manifestations.

The Southeast European Autism Network (SEAN) was established to enhance the lives of individuals with ASD and related neurodevelopmental disorders in Southeast Europe. As an initial step, a survey was developed by Autism Speaks in collaboration with the National Coordinators for Autism from eight countries to better understand the needs of, and challenges faced by, families in order to be able to set meaningful priorities for future efforts. SEAN was first launched in Albania in 2010 and comprises nine member countries: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Kosovo, Macedonia, Montenegro, Romania and Slovenia. Turkey is affiliated as an observer country. In each country, the Ministry of Health (or in some cases the Ministry of Education or Social Welfare) appoints a National Coordinator as a focal point; representatives from Autism Speaks serve as technical advisors (Autism Speaks and SEAN Network Report, September, 2015).

The Republic of Macedonia<sup>1</sup> is an upper middle-income country that has made great strides in reforming its economy over the past decade. The country became a European Union (EU) candidate in 2005, and since 2009 the European Commission (EC) has recommended opening accession negotiations. However, the decision continues to be postponed. The national population is 2.1 million, with Macedonian as the official and most widely spoken language. Three other main language groups include Albanian, Turkish and Romani. Skopje is the capital and contains almost half of the national population. The GDP per capita annual income is just under 5000 USD. There are significant economic disparities across regions, reflected in children's education and provision of health and human services. The terrain is geographically rugged defined by a central valley framed along its borders by mountain ranges, making access difficult. Three large lakes bisect the southern borders with Albania and Greece. The population of children and adolescents (0-14 years) is 19.2%; school attendance rates tend to be high (93%), although lower for minority groups. Schools are poorly accessible for disabled children.

This report presents the findings of the SEAN Caregiver Needs Survey for the Republic of Macedonia.

## METHODOLOGY

The survey about the parents/caregivers needs was performed using a questionnaire specially designed by the nine members of the SEAN network. The questionnaire included 57 questions in the following four domains: demographic characteristics, index child characteristics, service encounters and parent/caregiver perceptions. The majority of survey questions and responses were drawn from existing population-based surveys on children with special health care needs, including ASD. Ethics board approval was obtained from the Medical Faculty, Skopje; no identifiers were included in survey responses by consenting parents and caregivers. In this study, 60 parents/caregivers affected by ASD were recruited from institutions and schools where children with ASD were receiving services. Surveys were filled out anonymously and voluntarily. Autism Speaks

provided a small gift for participating families. The research phases consisted of initial development of the SEAN survey questionnaire with translation/back translation, agreement on ASD inclusion criteria based on caring for a child with DSM-IV-TR/ICD-10 Autistic Disorder, Asperger Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); pilot testing and approval of the final survey form; and survey distribution to a convenience sample of parent/caregiver groups drawn from the University Children's Hospital clinic, kindergartens, special schools, and health care centers/clinics where children with ASD were receiving services.

We conducted descriptive analyses and non-parametric Spearman correlation analyses to examine whether current age of the child was associated significantly with time-to-diagnosis. We also conducted linear regression analysis and the *t*-test to measure the effects of diagnosis, parental education, time to diagnosis, and current age of the child on impact of the disorder and level of difficulties reported by the parents.

## RESULTS

In this section we present the most significant results obtained from the survey.

**Table 1.** Family demographic characteristics\*

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
<b>Relationship to child</b>	
Mother	47 (80%)
Father	12 (20%)
Other	0 (0%)
<b>Highest level of education</b>	
Primary school	0 (0%)
Secondary school	22 (37%)
Some college/university	30 (50%)
College/university degree	6 (10%)
Higher than college	1 (2%)
<b>Spouse's highest level of education</b>	
Primary school	1 (2%)
Secondary school	21 (36%)
Some college / university	31 (53%)
College / university degree	5 (8%)
Higher than college	1 (2%)

\* Totals may not add up to 60 due to missing data

<sup>1</sup> Since the survey was conducted in 2015 and 2016, the previous official name of the country (the Republic of Macedonia) will be used in this paper as emphasized by the Editorial Board.

**Table 2. Basic child characteristics\***

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
<b>Gender</b>	
Male	56 (93%)
Female	4 (7%)
<b>Age in years, mean (SD)</b>	5.7±3.7SD
<b>Current diagnosis</b>	
Autism/Autistic disorder	26 (43.3%)
Asperger's syndrome	4 (6.6%)
PDD-NOS	1 (1.6%)
PDD	0 (0%)
ASD	25 (41.66%)
Other	4 (6.6%)
<b>Verbal ability</b>	
Does not talk	22 (37%)
Uses single words only	17 (29%)
Uses 2- or 2-word phrases	12 (20%)
Uses >4 word-sentences	2 (3%)
Uses complex sentences	7 (12%)

\* Totals may not add up to 60 due to missing data

**Table 3. Diagnosis\***

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
<b>Age at diagnosis in months, mean ± SD</b>	35.3±14.3
<b>Diagnosed by</b>	
Primary care doctor	0 (0%)
Pediatrician	6 (9%)
Psychologist	29 (44%)
Psychiatrist	4 (6%)
Neurologist	6 (9%)
Nurse	0 (0%)
Team of professionals	20 (30%)
Other	1 (2%)
<b>Distance for diagnosis</b>	
Less than 25 kilometers	47 (80%)
25-50 kilometers	2 (3%)
50-100 kilometers	4 (7%)
More than 100 kilometers	3 (5%)
Traveled outside the country	3 (5%)

\* Totals may not add up to 60 due to missing data

Descriptive analyses: In the Republic of Macedonia, SEAN survey took place from December 2014 to September 2015.

Of the total of 60 children with ASD, 56 or 93.3% were males. The distribution of ASD diag-

**Table 4. First concern**

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
<b>Age of child at first concern in months, mean ± SD</b>	20.1±7.0
<b>Nature of first concern</b>	
Had medical problems, e.g. seizures	5 (8%)
Did not make eye contact	44 (73%)
Did not respond to name when called	46 (77%)
Did not seem to understand non-verbal communication	23 (38%)
Had behavioral difficulties, e.g. tantrums	23 (38%)
Had problems with coordination / gross motor skills	6 (10%)
Talked later than usual for most children	12 (20%)
Was not talking at all	24 (40%)
Did not talk as well as other children of same age	22 (37%)
Some speech / skills were lost	30 (50%)
Did not seem to understand what adults said to him/her	26 (43%)
Had problems with fine motor skills, e.g. drawing with crayons	15 (25%)
Had difficulty playing or interacting with others	50 (83%)
Insisted on sameness / had difficulty with change	33 (55%)
Had difficulty learning new skills, e.g. toilet training	18 (30%)
Had difficulty learning new things, e.g. the alphabet	14 (23%)
Made unusual gestures or movements, e.g. hand-flapping	39 (65%)

**Table 5. Past and current service providers\***

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
Audiologist	10 (17%)
Neurologist	38 (63%)
Nutritionist	15 (25%)
Psychiatrist	20 (33%)
Psychologist	49 (82%)
Other	7 (12%)

\* Totals may not add up to 60 due to missing data

noses was: Autism/Autistic disorder, 26 children (43.3%); Asperger's disorder, 4 children (6.6%); PDD-NOS, 1 child (1.6%); Autism Spectrum Disorder, 25 children (41.66%); and Other, 4 children (6.6%). Caregiver-reported verbal ability of affected children ranged from no talking at all to

**Table 6.** School enrollment for children > 5 years

Characteristic	N (%)
<b>Subject</b>	42 of 60
Preschool	9 (21%)
Public primary school	1 (2%)
Private school	7 (17%)
Special school for children with disabilities	25 (60%)
Home schooled	-
Not enrolled in school	0 (0%)

**Table 7.** Other services/assistance

Characteristic	N (%)
<b>Subjects</b>	60 (100%)
Receiving training/assistance	10 (17%)
Receiving government aid	37 (64%)
Participate in advocacy groups	11 (19%)
<b>ASD information sources</b>	
Internet	53 (88%)
Child's doctor	12 (20%)
Child's teacher	17 (28%)
Other ASD parents	41 (68%)
Other providers	47 (78%)
Other	3 (5%)

\* Totals may not add up to 60 due to missing data

using two-word phrases (n=51; 85%), to using sentences with at least four words (n=9; 15%). The survey involved parents among whom 22 or 36.7% had secondary education. Most parents had some college education (n=30; 50%) or beyond (n=7; 11.7%).

Mean age ( $\pm$  SD) of the cases was 89.8 $\pm$ 49.9 months (range, 30-192). The mean age ( $\pm$  SD) at diagnosis was 35.3 $\pm$ 14.3. The mean age at first concern in parents was considerably lower at 20.1 $\pm$ 7 months (range, 3-36). The parents of all the study children therefore had some concern prior to three years of age. Average time from first concern to diagnosis was 15.2 $\pm$ 15.7 months (range, 0-78), suggesting great variation in time prior to ASD diagnosis. The most common first concerns included difficulty playing/interacting with others (83%), not responding to the child's own name (77%), poor eye contact (73%), unusual gestures/walking/posture (65%) and insistence on sameness/difficulty with change (55%). The primary challenges ranked by families include poor communicational skills (40%), difficulties in social interactions (35%) and stereotyped behaviors of the child (33.33%)

Among several difficulties reported by parents that had led to delayed service use were: high cost, lack of information, unavailability of services, ineligibility for services, and wait-lists. The most commonly reported difficulty was delays due to costs (33.3%). It was interesting to note that 50% of the families did not report any difficulties, while almost 23% of the families reported three or more difficulties, with these families experiencing a range of frustration levels. The most commonly reported impact was financial difficulties (75%). Eighty percent of the families strongly agreed or agreed that they have some self-stigmatization about having a child with ASD diagnosis. The most common concerns included: feeling helpless (24%), followed by fear of discrimination (66%), having a negative impact (28%) and worrying about other people knowing the diagnosis (65%).

In terms of services, 81.66% of the children received combination of sensory, speech/language treatments, and medications. Treatments were typically provided by private special educators and rehabilitators, and the majority (78.57%) of parents were paying full amount for months or years. Most of the children were attending state kindergartens (40%) and special schools (41.66%). Parents reported that they obtained ASD information mainly from the internet (88%), professionals (78%) and other parents (68%). ASD caused serious financial problems for the families (75%) as well as emotional issues for the parents (70%). Parents ranked their challenges as: need for improved health care services (72.41%), educational opportunities (65%) and enhanced social care (51.66%).

The major source of dissatisfaction among the families in terms of quality of life was that their children lacked support to make friends (37%). Nearly two-thirds (63.8%) of the families reported receiving financial support from the government.

Non-parametric Spearman correlation analysis: We examined the association of current age, age at diagnosis, time-to-diagnosis, type of diagnosis, parental education, financial support and satisfaction, difficulties, impact and stigma. The non-parametric Spearman correlation analysis showed that current age of the child was associated significantly with time-to-diagnosis ( $\rho=0.75$ ,  $p<0.001$ ). This suggested that families of older children spent sig-

nificantly more time moving from first concern to diagnosis. This may imply that diagnostic services have improved in the Republic of Macedonia. At the same time, families with older children reported less overall satisfaction ( $\rho = -.31$ ,  $p = .014$ ), implying greater recognition of the difficulties they faced.

The level of frustration in efforts to get services showed significant associations with satisfaction ( $F(df:2.55) = 4.3$ ,  $p = .02$ ), difficulties and unmet needs ( $F(df:2.56) = 13.5$ ,  $p < .001$ ), and impact of the disorder on the family ( $F(df:2.52) = 3.3$ ,  $p = .048$ ). Time to diagnosis was also longer among families who reported higher levels of frustration ( $F(df:2.54) = 3.3$ ,  $p = .046$ ).

Parents of children with the Autistic Disorder subtype reported less satisfaction ( $F(df:1.58) = 5.0$ ,  $p = .029$ ), and more stigmatization ( $F(df:1.58) = 5.8$ ,  $p = .019$ ), when compared with children with other autism spectrum disorders. Thus, among the three categories in the DSM-IV-TR/ICD-10 classification, the subtype Autistic Disorder is the most severe.

Parental education was associated with current age of the child and with time from first concern to diagnosis. Children of parents with college education were younger ( $F(df:2.58) = 5.3$ ,  $p = .008$ ) and time to diagnosis was shorter ( $F(df:2.58) = 3.2$ ,  $p = .050$ ), suggesting better diagnostic assessment in this group.

Financial support by the government was associated with higher impact of the disorder on the family ( $F(df:1.55) = 8.1$ ,  $p = .006$ ), level of difficulties and unmet needs ( $F(df:1.58) = 4.7$ ,  $p = .034$ ), and longer time to diagnosis ( $F(df:1.58) = 5.7$ ,  $p = .019$ ). This suggests that financial aid had appropriately targeted more vulnerable families. Nonetheless, it was beyond the scope of the current project to assess the effectiveness of the aid.

Linear regression analysis and t-test: As a preliminary analysis, we also conducted linear regression analysis to measure the effects of diagnosis, parental education, time-to-diagnosis, and current age of the child on impact of the disorder and level of difficulties reported by the parents. Linear regression analysis showed that higher satisfaction with services was associated with having younger children ( $B = 2.808$ ,  $p < 0.01$ ), and higher parental education was associated with lower impact of the condition (for mothers,  $B = 1.819$ ,  $p < 0.01$ ; for fathers,

$B = 3.358$ ,  $p < 0.05$ ). Additionally, the *t*-test showed that parent satisfaction was higher for children with ASD diagnosis overall than for children diagnosed with Autistic Disorder ( $t = -2.895$ ,  $p < 0.01$ ).

## DISCUSSION

When their child is diagnosed with ASD, many parents experience disbelief or profound sadness and depression, self-blame and guilt, helplessness, feelings of inadequacy, anger, shock and guilt (Gupta & Singhal, 2005).

In general, as in our survey, the majority of families with ASD children face daily difficulties and challenges, aggravated by the behavioural, cognitive, social and emotional issues associated with the disorder. This way of living has adverse effects on various domains of family life, like marital interactions, sibling relationships and adjustment, family socialization practices as well as normal family routines (Greeff & Walt, 2010). Research suggests that parents of ASD children are predominantly vulnerable to negative outcomes and reduced feeling of happiness. They experience higher levels of depressive symptoms (Abbeduto et al., 2004), stress (Weiss, 2002) and negative impact (Blacher & McIntyre, 2006) than the parents of children with other developmental disorders. Higher vulnerability to stress can affect the child's development and condition.

Levels of distress are higher in mothers than fathers, as stated in some studies (Sloper & Turner, 1993), reflecting that mothers are usually the ones dealing more with the child's everyday life. Pisula and Kossakowska (2010) found that mothers of children with autism spent an average of 9.5 hours per day caring for their child, compared to 5.3 hours for parents of typically developing children. This astonishing amount of caregiving can take a cumulative toll. Even though most of the fathers acknowledge the impact of autism on their families, they usually state that it did not have a significant effect on them personally. For them, the most serious effect was the stress experienced by their wives. This could be explained due to the gender roles connected to work and helping the family and the child to reach financial independence (Gray, 2003). In our study, 70% of the parents stated that ASD in their child provoked emotional issues for them.

Research has proven that family stress can contribute to unfavorable prognosis. Family stress associated with financial difficulties, lack of appropriate services and insufficient support systems are examples of family system risk factors that can contribute to poor prognosis (Seifer et al., 1992). ASD children require support in home settings, school facilities and the community. Even as adults, they will need constant supervision in order to keep themselves safe. This is an additional burden on their families. Because of the high requirements associated with taking care of an autistic child, in many cases parents do not have enough personal time, which can result in a deteriorated relationship between the parents, abandonment of one of the parents from the responsibilities towards the child and eventually to divorce. Therefore, in helping ASD children, the focus should be on their families too, addressing not only family difficulties but also factors that can contribute to healthy family functioning. Research has found that addressing the entire family system, rather than focusing exclusively on the child, may result in improved outcomes for the family (Smith et al., 2010).

It is noticeable that the more severe the child's clinical manifestations are, the more severe is parents' exposure to stress. This can lead to greater isolation of the child and his or her family and to absenteeism from school activities, social events and the workplace. The feeling of not having control over the child or one's own life enhances the sense of helplessness. Gray (1993) found that almost all parents with ASD children felt stigmatized in public situations, especially parents of younger severely disabled children. Consequently, those parents frequently receive hostile and thoughtless reactions from the public, and are perceived as bad parents. In our study, 65% of the parents stated that they felt worried about whether other people would know that they had a child with autism, and 66% endorsed the statement that other people would discriminate against them because they had a child with autism. On the other hand, only 28% of the families in our study strongly agreed or agreed that having a child with autism would impose a negative impact on them, and only 24% strongly agreed or agreed that they felt helpless because they had a child with autism. Empowerment of parents is one of the factors that can influence

their responses to daily challenges related to parenting an ASD child. This can lead to positive outcomes, including increased parental self-esteem and better control over the environment.

Research also suggests that siblings of ASD children are at risk of experiencing psychological and emotional impact too, as they grow up in a family with an autistic child. Often, siblings feel neglected, since more time and attention are given to the child with autism. This can evoke ambivalent feelings towards the ASD sibling; anger, rebellion and resentment towards the parents; and a feeling of loneliness. Various psychiatric conditions appear more than twice as often in families with ASD children than in the general population. It is now known that ASD shares genetic roots with some psychiatric and developmental disorders (Smoller et al., 2013). Some studies have even shown that almost half of siblings of ASD children have attention problems, language difficulties, learning issues or mood swings, even if they don't have signs of ASD (Miller et al., 2016). This implies, again, that addressing the entire family system rather than only the ASD child will lead to better outcomes.

Besides the family stress accompanying the disorder, autism also has huge financial implications. Many families spend large sums for years on various treatments for their child. Many treatments are expensive and last for years. They may spend significant amounts on appropriate and supportive educational programmes. Additional activities such as sports and leisure involve additional costs. Furthermore, many families seek and pay for alternative treatments, food supplements, special diets and various alternative physical examinations. In our study, 75% of the families reported that their child's autism had caused significant financial problems, due to lack of high-quality public services and the need to pay private therapists.

We must state that in our study, 92% of the surveyed families were primarily from the capital city Skopje (92%) and only 8% from the other cities in the country. Skopje has the most developed public and private services, so we need to extend our research to families in other parts of the country, in order to identify resilience factors in families that do not have access to such services.

## CONCLUSION

The survey results underscore that parents and families of children with ASD in the Republic of Macedonia carry a heavy burden. The parents and caregivers of ASD children face significant financial difficulties and need improved services from the health, educational and social sectors.

The finding of average age at first diagnosis of 35.3 months is quite remarkable. The average age at first concern in parents was considerably lower (20.1 months). The parents of all the study children therefore had some concern prior to three years of age. Although the average age of the child when parents first became concerned is similar to the average age in US studies, the average age at diagnosis is lower in the SEAN survey for Macedonia than in most US and Western European studies. While the low age at diagnosis may be due in part to selection bias, since caregivers were identified through the use of existing ASD services, 17% of caregivers reported traveling 50 km or more to receive a diagnosis for their child, which is a considerable distance given the difficult geography of Macedonia. In addition, approximately one-third of all caregivers reported difficulties or delays in accessing needed care because of issues related to cost, and the majority (75%) reported that their child's autism had created financial problems for the family. Lastly, 60% of ASD children were enrolled in schools specifically for children with disabilities. These data indicate that inclusive education is more the exception than the rule in the surveyed region during the survey period.

Higher satisfaction was associated with having younger children and having an overall ASD diagnosis rather than diagnosis of Autistic Disorder. Parental education was associated with lower impact of the disorder on the family; however, it is notable that many of the parents had college and higher education (61.7%).

The families of older children took significantly more time to move from first concern to diagnosis. This may imply that diagnostic services have improved in the Republic of Macedonia. On the other hand, families with older children reported less overall satisfaction, implying awareness of, and adjustment to, the difficulties. In fact, level of

frustration in efforts to get services was significantly associated with satisfaction, difficulties and unmet needs, and impact on the family. Indeed, the time to diagnosis was also longer among families who reported higher level of frustration. The parents of children with Autistic Disorder subtype reported less satisfaction and more stigmatisation than the parents of children with other autism spectrum disorders overall. Among the three categories in the DSM-IV-TR/ICD-10 classification, Autistic Disorder subtype is the most severe. This observation also endorses the consistent validation of the ASD diagnostic scheme applied in the SEAN survey.

There is a critical need to strengthen national capacity in caring for children, young people and adults with ASD and other neurodevelopmental disorders in the Republic of Macedonia. To accomplish this objective, national policies can engage in a variety of activity. One activity is to increase awareness and encourage early detection and diagnosis of ASD, as well as facilitate access to services as early as possible. The country has clearly been quite receptive to knowledge garnered in ASD, but this needs to be distributed across all socioeconomic strata (Durkin et al., 2015). A second activity is to ensure access to evidence-based therapies by providing additional training to parents, teachers and clinicians in the most effective interventions (Zwaigenbaum et al., 2015). A third activity is to provide those with ASD and neurodevelopmental disorders access to public education, with the goal of inclusion. A fourth activity is to ensure that families of those with ASD and neurodevelopmental disorders have the appropriate support and information to care for their family members (Hecht et al., 2011). A fifth activity is to encourage participation in high-quality research, health surveillance and dissemination of research findings to obtain a full and accurate picture of the needs and challenges faced by parents and caregivers.

## ACKNOWLEDGMENTS

The author wish to acknowledge Autism Speaks and the collaborating countries in the Southeast European Autism Network (SEAN) for contributions to the development and implementation of the Caregiver Needs Survey. We are grateful to the parents and families who participated in the survey.

## REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., Murphy, M. M., et al. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, *109*, 237-254.
- Baxter, A.J., Brugha, T.S., Erskine, H.E., Scheurer, R.W., Vos, T., Scott, J.G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, *45*(3), 601-13.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, *50*, 184-198.
- Brugha, T.S., McManus, S., Bankart, J., et al. (2011). Epidemiology of autism Spectrum Disorders in Adults in the Community in England. *Archives Of General Psychiatry*, *68*, 459-466.
- Durkin, M.S., Elsabbagh, M., Barbaro, J., Gladstone, M., Happe, F., Hoekstra, R.A. et al. (2015). Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. *Autism Research*, *8*(5), 473-6.
- Elsabbagh, M., Divan, G., Koh, Y.J., Kim, Y.S., Kauchali, S., Marcin, C. et al. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, *5*(3), 160-179.
- Gray, D.E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, *15*, 102-120.
- Gray, D.E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, *56*, 631-642.
- Greeff, P.A. & Walt, K-J. (2010). Resilience in Families with an Autistic Child. *Education and Training in Autism and Developmental Disabilities*, *45*(3), 347-355.
- Gupta, A. & Singhal, N. (2005). Psychosocial support for families of Children with Autism. *Asia Pacific Disability Rehabilitation Journal*, *16*(2), 62-83. Retrieved from <http://www.aifo.it/english/disability/apdrj/apdrj205/autism.pdf>.
- Hecht, E., Reynolds, M., Agosta, J., McGinley, K. (2011). Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6–8. Racine, WI: Johnson Foundation. Available at: <http://issuu.com/supportstofamilies/docs/wingspreadreport-2012-rev-52912-com/11?e=11660291/7532630>
- Centers for Disease Control and Prevention (2018). Morbidity and Mortality Weekly Report (MMWR): Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network. Retrieved from <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm>.
- Kim, Y.S., Leventhal, B.L., Koh, Y., et al. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, *168*, 904-912.
- Miller, M., Iosif, A.M., Young, G.S., Hill, M., Phelps Hanzel, E., Hutman, T., Johnson, S., Ozonoff, S. (2016). School-age outcomes of infants at risk for autism spectrum disorder. *Autism Research*, *6*, 632-42. doi: 10.1002/aur.1572.
- Pisula, E., & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism and Developmental Disorders*, *40*, 1485-1494.
- Seifer, R, Sameroff, AJ, Baldwin, CP, Baldwin, AL. (1992). Child and family factors that ameliorate risk between 4 and 13 years of age. *Journal of American Academy of child and Adolescent Psychiatry*, *31*, 893-903.
- Sloper, P., Turner, S., (2010). Risk and resistance factors in the adaptation of children with severe physical disability. *Journal of Child Psychology and Psychiatry*, *34*, 167-18.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*, 167-178.



Smoller, JW et al. (2013). Identification of risk loci with shared effects on five major psychiatric disorders: a genome-wide analysis. *Lancet*, 381(9875), 1371-9. doi: 10.1016/S0140-6736(12)62129-1.

The Southeast European Autism Network (SEAN) Caregiver Needs Survey. Albania, Croatia, Macedonia, Romania & Turkey: Preliminary Findings. A Joint Autism Speaks and SEAN Regional Report, September 2015.

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6(1), 115-130.

Zwaigenbaum L, Bauman ML, Choueiri R, Kasari C, Carter A, Granpeesheh D et al. (2015). Early intervention for children with autism spectrum disorder under 3 years of age: Recommendations for practice and research. *Pediatrics*, 136 (Suppl 1), S60–81.