

MAIN NEEDS AND CHALLENGES OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Tatjana Zorcec¹ and Nada Pop-Jordanova²

¹ University Children's Hospital, Skopje

² Macedonian Academy of Sciences and Arts, Skopje, R.N. Macedonia

Corresponding author: Nada Pop-Jordanova, Bul Krste Misirkov br.2, P.O.Box 428, 1000 Skopje, North Macedonia, e-mail: popjordanova.nadica@gmail.com

ABSTRACT

Autism spectrum disorder (ASD) comprises a group of complex lifelong neurodevelopmental disorders, characterized with symptoms related to the difficulty of communication and interaction with other people, as well as restricted interests and repetitive behaviors. These symptoms affects the person's ability to function properly in school, work, and other areas of life.

For better understanding the needs and challenges of families the survey developed by Autism Speaks in collaboration with the National Coordinators for Autism from nine Balkan countries was established. The aim of this research is to obtain an overview of some important data for children with some form of autistic disorder.

The same questionnaire was used in two different periods of time (during 2015 and at the beginning of 2020) including samples of 60 and 140 parents respectively.

The questionnaire comprises 57 questions in the following four domains: demographic characteristics, index child characteristics, service encounters and parent/caregiver perceptions. Results are compared and discussed.

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

It was concluded that there is a critical need to strengthen national capacity in caring for children, young people and adults with ASD and other neurodevelopmental disorders.

Keywords: autism spectrum disorder, children, survey, needs

INTRODUCTION

Autism spectrum disorder (ASD) comprises a group of complex lifelong neurodevelopmental disorders, characterized with symptoms related to difficulty of communication and interaction with

other people, as well as restricted interests and repetitive behaviours. These symptoms affects the person's ability to function properly in school, work, social and other areas of life.

Autism spectrum disorder (ASD) has a variety of causes, and its clinical expression is generally associated with substantial disability throughout the lifespan. Recent advances have led to earlier diagnosis, and deep phenotyping efforts focused on high risk infants which may help the advance and characterization of early behavioural trajectories.

The statistics about the incidence differs, depending on country and region. In the United States of America, the Centre for Disease Control and Prevention (CDC) in 2018 published that one in 54 children manifest ASD (<https://www.cdc.gov/ncb-ddd/autism/data.html>). Prevalence of 1% and even higher is mentioned in the United Kingdom (Brugha TS, McManus S, Bankart J, et al. 2011). In some Asian countries (Kim YS, Leventhal BL, Koh Y et al. 2011) the incidence is supposed to be from 1.81% to 2.6%. 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).

In absence of specific biological markers, this condition continues to be defined by its behavioural manifestations mentioned as core criteria in diagnostic manuals as the International Classification of Diseases (ICD) or Diagnostic and Statistical Manual of Mental Disorders (DSM). In 2013, the 5th revised version of the DSM (DSM5) was released. This revision changed the way autism is classified and diagnosed. In this context, children could be diagnosed with only one diagnosis – Autism Spectrum Disorder or ASD. Asperger's syndrome or Pervasive developmental disorder are no longer valid (American Psychiatric Association, 2013).

Autism is known as a “spectrum” disorder because there is a wide variation in the type and the severity of the symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function. The main purpose of all medical staff is to diagnose earlier as possible and to start with early rehabilitation and treatment of these children.

Every child should receive well-child check-ups with a paediatrician or an early childhood health care provider. The American Academy of Paediatrics recommends all children to be screened for developmental delays at their 9-, 18-, and 24- or 30-month well-child visits and specifically for autism at their 18- and 24-month well-child visits. Additional screening might be needed if a child is at high risk for ASD or developmental problems (<https://www.aafp.org/afp/2017/0701/p36.html>). Those at

high risk include children who have a family member with ASD, have some ASD behaviours, have older parents, have certain genetic conditions, or who were born at a very low birth weight.

The treatment for ASD should begin as soon as possible after diagnosis. Early treatment for ASD is important as proper care can reduce individuals' difficulties while helping them learn new skills and make the most of their strengths. The wide range of issues facing people with ASD means that there is no single best treatment for ASD. Working closely with a doctor or health care professional is an important part of finding the right treatment program.

For better understanding the needs and challenges of families in order to be able to set meaningful priorities for future efforts, the survey developed by Autism Speaks in collaboration with the National Coordinators for Autism from eight Balkan countries was established in 2010. Nine countries (Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Kosovo, Macedonia, Montenegro, Romania and Slovenia, and Turkey as an observer country) started collaboration in this topic establishing South East Autism Network (SEAN network).

The Republic of North Macedonia is an upper middle-income country having the population of 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 5.000 USD. There are significant economic disparities across regions, reflected in children's education and provision of health and human services.

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. Still, schools are poorly accessible for disabled children.

METHODOLOGY

The purpose of SEAN network was to enhance the lives of individuals with ASD and related neurodevelopmental disorders in Southeast Europe. Hence, a survey about the parents/caregiver's needs was performed using a questionnaire specially designed for this purpose. 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.

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 implementation with parent/ caregiver groups comprised of a convenience sample drawn from the University Children's Hospital clinic-Skopje, health care centers/clinics where children with ASD are evaluated and treated, kindergartens and special schools too.

The same questionnaire was used in two different period of time (during 2015 and at the beginning of 2020). 60 families were assessed in the first period, and in the second the number of families was much greater i.e. N= 140.

Ethics board approval was obtained from the Medical Faculty, Skopje; Surveys were filled out anonymously and voluntarily by parents/caregivers of children affected by ASD, recruited from institutions and schools where children with ASD were receiving services.

The obtained results for both evaluated groups will be presented in tables and discussed. Simple statistics was applied using Statistic package 10.

RESULTS

The difference between groups is calculated using Student t-test. The bold red letters, in cells presenting "p" values, indicate that there is a significant statistical difference between the two groups.

Family demographic characteristics for both evaluated samples are presented in Table 1.

Table 1. Family demographic characteristics

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Relationship to child			
Mother	47 (80%)	130 (93%)	p = 0.0070
Father	12 (20%)	9 (6%)	p = 0.0304
Other	0 (0%)	1 (1%)	p = 0.4381
Highest level of education			
Primary school	0 (0%)	1 (1%)	p = 0.4381
Secondary school	22 (37%)	72 (51%)	p = 0.0697
University degree	36 (10%)	61 (44%)	p < 0.0001
Higher than university degree	1 (2%)	6 (4%)	p = 0.4756
Spouse's highest level of education			
Primary school	1 (2%)	0 (0%)	p = 0.0941
Secondary school	21 (36%)	72 (51%)	p = 0.0519
University	36 (53%)	57 (41%)	p = 0.1186
Higher than university degree	1 (2%)	9 (6%)	p = 0.2264

Basic child characteristics are presented in Table 2.

Table 2. Basic child characteristics

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Gender			
Male	56 (93%)	119 (85%)	p = 0.1191
Female	4 (7%)	21 (15%)	p = 0.1191
Age in years, mean (SD)	5.7±3.7SD	7.16±4.29	p = 0.0006
Current diagnosis			
Autism/ Autistic disorder	26 (43.3%)	95 (68%)	p = 0.0009
Asperger's syndrome	4 (6.6%)	5 (4%)	p = 0.5371
PDD-NOS	1 (1.6%)	0 (0%)	p = 0.2372
PDD	0 (0%)	18 (13%)	p = 0.0035
ASD	25 (41.66%)	15 (11%)	p < 0.0001
Other	4 (6.6%)	7 (5%)	p = 0.7729
Verbal ability			
Does not talk	22 (37%)	64 (46%)	p = 0.2403
Uses single words only	17 (29%)	37 (26%)	p = 0.6619
Uses 2- or 2-word phrases	12 (20%)	23 (16%)	p = 0.4932
Uses >4 word-sentences	2 (3%)	11 (8%)	p = 0.1898
Uses complex sentences	7 (12%)	5 (4%)	p = 0.0346

Information related to diagnostics, age and professionals included are presented in Table 3.

Table 3. Diagnosis

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Age at diagnosis in months, mean (SD)	35.3±14.3	27,64±14,59	p = 0.0003
Diagnosed by			
Primary care doctor	0 (0%)	0 (0%)	
Pediatrician	6 (9%)	1 (1%)	p = 0.0043
Psychologist	29 (44%)	73 (52%)	p = 0.3010
Psychiatrist	4 (6%)	2 (1%)	p = 0.0384
Neurologist	6 (9%)	3 (2%)	p = 0.0225
Nurse	0 (0%)	0 (0%)	
Team of professionals	20 (30%)	58 (41%)	p = 0.1423
Other	1 (2%)	3 (2%)	p = 1.0000
Distance for diagnosis			
Less than 25 kilometers	47 (80%)	80 (57%)	p = 0.0020
Between 25-50 kilometers	2 (3%)	18 (13%)	p = 0.0312
Between 50-100 kilometers	4 (7%)	16 (11%)	p = 0.3845
More than 100 kilometers	3 (5%)	19 (14%)	p = 0.0661
Traveled outside the country	3 (5%)	7 (5%)	p = 1.0000

When and which signs provoked the first concern about the disorder is shown in Table 4.

Which professionals were included in the management of problems is presented in Table 5.

Table 5. Current service providers

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Audiologist	10 (17%)	2 (1%)	p < 0.0001
Neurologist	38 (63%)	61 (44%)	p = 0.0140
Nutritionist	15 (25%)	10 (7%)	p = 0.0004
Psychiatrist	20 (33%)	37 (26%)	p = 0.3141
Psychologist	49 (82%)	95 (68%)	p = 0.0434
Rehabilitator	49 (82%)	134 (96%)	p = 0.0010
Other	7 (12%)	9 (6%)	p = 0.1481

Attendances to kindergarten and school is presented in Table 6.

Table 4. First concern

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Age of child at first concern in months, mean (SD)	20.1±7.0	21,17±6,09	p = 0.3060
Nature of first concern			
Medical problems, i.e. seizures	5 (8%)	39 (28%)	p = 0.0018
Didn't make any eye contact	44 (73%)	106 (76%)	p = 0.6538
Didn't respond to name when called	46 (77%)	117 (84%)	p = 0.2399
Didn't seem to understand non-verbal communication	23 (38%)	95 (68%)	p = 0.0001
Had behavioral difficulties, i.e. tantrums	23 (38%)	70 (50%)	p = 0.1198
Had problems with coordination / gross motor	6 (10%)	12 (9%)	p = 0.8239
Talked later than usual for most children	12 (20%)	39 (28%)	p = 0.2360
Was not talking at all	24 (40%)	64 (64%)	p = 0.0017
Did not talk as well as other children of same age	22 (37%)	48 (34%)	p = 0.6841
Some speech / skills were lost	30 (50%)	64 (46%)	p = 0.6045
Didn't seem to understand what adults said to him/her	26 (43%)	101 (72%)	p = 0.0001
Had problems with fine motor skills, i.e. drawing with crayons	15 (25%)	69 (49%)	p = 0.0017
Had difficulty playing or interacting with others	50 (83%)	115 (82%)	p = 0.8655
Insisted on sameness / had difficulty with change	33 (55%)	99 (71%)	p = 0.0288
Had difficulty learning new skills, i.e. toilet training	18 (30%)	86 (61%)	p = 0.0001
Had difficulty learning new things, i.e. the alphabet	14 (23%)	17 (12%)	p = 0.0482
Had unusual gestures of movements, i.e. hand-flapping	39 (65%)	117 (84%)	p = 0.0029

Table 6. *School enrollment*

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Preschool	10 (16%)	79 (56%)	p < 0.0001
Public primary school	19 (32%)	37 (26%)	p = 0.3866
Private school	7 (11%)	1 (1%)	p = 0.0010
Special school for children with disabilities	25 (41%)	13 (9%)	p < 0.0001
Not enrolled in school	0 (0%)	10 (7%)	p = 0.0361

In Table 7 we present other services included in the management of ASD children.

Table 7. *Other services/assistance*

Characteristic	N (%)	N (%)	p
Subjects	60	140	
Receiving training/assistance	10 (17%)	16 (17%)	p = 1.0000
Receiving government aid	37 (64%)	80 (57%)	p = 0.3574
Participate in advocacy groups	11 (19%)	15 (11%)	p = 0.1290
ASD information sources			
The Internet	53 (88%)	126 (90%)	p = 0.6745
My child's doctor	12 (20%)	50 (36%)	p = 0.0256
My child's teacher	17 (28%)	52 (37%)	p = 0.2203
Other ASD parents	41 (68%)	117 (84%)	p = 0.0108
Other providers	47 (78%)	119 (85%)	p = 0.2294
Other	3 (5%)	0 (0%)	p = 0.0078

Descriptive analyses

Parents from both groups reported a delay in using service in the country due to high costs (33% in the first group versus 46% in the second group), lack of information (41% in the first group versus 49% in the second group), unavailability of services in the public institutions (65% in the first group versus 73% in the second group) and long waiting lists (57% in the first group versus 56% in the second group).

The most common reported negative impact was on family finances (75% in the first group versus 76% in the second group). Families in the first group in 80% strongly agreed or agreed that they have some self-stigmatization about having a child with ASD diagnosis versus 79% in the second group.

The most shared concerns included feeling helpless (24% in the first group versus 26% in the second group), fear of discrimination (66% in the first group versus 76% in the second group), experiencing negative impact on personal life (28% in the first group versus 37% in the second group) and concerns on other people knowing

the diagnosis (65% in the first group versus 66% in the second group).

In terms of receiving services, 81% in the first group versus 86% in the second group used sensory, speech and language treatments and pharmacotherapy.

Treatments were mainly received in private institutions and paid without use of health insurance (78% in the first group versus 85% in the second group).

Large majority of the parents reported that they are informed about ASD mainly from the internet (88% in the first group versus 90% in the second group) or from other parents (68% in the first group versus 74% in the second group) or other providers (78% in the first group versus 85% in the second group).

Emotional difficulties were experiences by majority of the parents (70% in the first group versus 74% in the second group).

Parents ranked the challenges as follows: need for improvement of the health care services (72% in the first group versus 82% in the second group), educational services (65% in the first group versus 72% in the second group) and social care (51% in the first group versus 54% in the second group).

In terms of quality of life, majority of the families reported lack of support to make friends among peers (37% in the first group versus 54% in the second group) and support to improve at home (38% in the first group versus 51% in the second group).

Discussion

As mentioned, we evaluated two independent samples of families with ASD children in two periods of time. Mainly, the mothers completed the questionnaire, especially in the second period (p=0.0070). It was noted that there is a difference in the level of education, with university degree significantly much presented in the second period of evaluation (p<0.0001).

As expected, majority of the children are boys. The age of children at the moment of fulfilling the questionnaire in the second sample shows that they are for two years older (p=0.0006).

Significantly higher is the diagnosis of Autism disorder in the second sample (p=0.0009).

Additionally, there are significant difference in other diagnoses like PDD and ASD ($p=0.0035$ and $p<0.001$ respectively) which are much more present in the second sample.

Very important finding is the age of the establishing the ASD diagnosis, which is shown to be much earlier (for about 8 months) in the second sample ($p=0.0003$). In the first group average age was $35.3 (\pm 14.3)$ and in the second one $27.64 (\pm 14.5)$. In the first group, diagnosis was established significantly more by pediatrician than in the second group ($p=0.0043$) but mainly it is established by psychologists (44% in the first group versus 52% in the second group) or team of professionals (30% in the first group versus 41% in the second group).

Significant improvement was noticed in the distance from the institution where the diagnosis was established, with better results in the second testing ($p=0.0020$). In other words, families have not been obliged to travel long distance for assessment by the mental health workers.

The first concern for some developmental problems were mainly in the areas of social communication and repetitive behavior in both groups. Significantly more children in the second group had seizures ($p=0.0018$), difficulties in understanding the non-verbal ($p=0.0001$) and verbal communication ($p=0.0001$), not talking at all ($p=0.0017$), had difficulties in fine motor skills ($p=0.0017$), learning new skills like toilet training ($p=0.0001$) as well as unusual gestures like hand-flapping ($p=0.0029$). Furthermore, we have noticed that ASD children in the second group are more nonverbal (37% in the first group versus 46% in the second group), and less using complex sentences (12% in the first group versus 4% in the second group).

The further analysis of answers in the questionnaire shows that other service providers were much more involved in the first period of testing, like audiologists ($p<0.0001$), nutritionists ($p=0.0004$) but not rehabilitators too ($p=0.0010$). Parents are using the services of rehabilitators in present time significantly more.

It is important to accentuate that there are differences in both samples concerning inclusion in preschool institutions ($p<0.0001$), in private school ($p<0.0001$) as well as in special school ($p<0.0001$). However, in our country practically all disabled children are included in educational process.

It is also interesting to notice that second group of parents received less aid from the government (64% in the first group versus 57% in the second group) and participated less in the advocacy groups (19% in the first group versus 11% in the second group).

Autism is associated with serious burden and stress for the parents of the affected child. A day in the life of a parent with child with ASD can include many challenges and stressors. They need to drive their child to various appointments and services, advocate for the child's needs, helping their child cope with various difficulties and deal with an unexpected events. At the end of the long and difficult days, they need to put aside all the worries, try to get some rest and gain new strengths for the next day. As presented in our study, this level of stress is provoking negative impact on important domains of family life, like marital and siblings interactions and adjustment, social life as well as typical family routines (Greeff and Walt, 2010). Furthermore, those parents develop more depressive symptoms (Abbeduto et al., 2004), experience more stress (Weiss, 2002) and negative impact (Blacher & McIntyre, 2006) than the parents of children with other developmental disorders. Pisula and Kossakowska (2010) published that mothers of ASD children in average spend 9.5 hours daily in providing the ASD child versus to 5.3 hours for parenting a typical child, which is for sure having a cumulative toll. Obviously, the more severe ASD symptoms are expressed, the more severe family stress is. This can lead to severe social isolation, less school attending, more absence from work. Siblings are also having emotional toll as they develop in specific and stressful family surrounding. Some researchers published that almost half of siblings experience attention, learning and language difficulties and mood swings (Miller, et al., 2016). This suggests that mental health professionals should address the whole family rather than only the child with ASD.

CONCLUSIONS

These two surveys showed that families of children with ASD in the Republic of N. Macedonia carry a very heavy burden. They are facing significant financial problems and need improve-

ment of services in the health, educational and social sectors. Emotional stress is high in both groups as well as fear of stigma in the society. The average age of parent's first concern about child's development is still very low as well as average age of diagnosis establishment. The time to move from first concern to diagnosis in many children is very short and even improves in the second group. Those findings are very promising since early diagnosis is crucial in starting early intervention and providing better chances for positive output.

REFERENCES

1. <https://www.cdc.gov/ncbddd/autism/data.html>
2. Brugha TS, McManus S, Bankart J, et al. (2011) Epidemiology of autism Spectrum Disorders in Adults in the Community in England. *Arch Gen Psychiatry* 68: 459-466.
3. Kim YS, Leventhal BL, Koh Y, et al. (2011) Prevalence of autism spectrum disorders in a total population sample. *Am J Psychiatry* 168: 904-912.
4. Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott JG. (2015): The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45 (3): 601-13.
5. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
6. <https://www.aafp.org/afp/2017/0701/p36.html>
7. Greeff, P.A. and Walt, K-J. (2010): Resilience in Families with an Autistic Child. *Education and Training in Autism and Developmental Disabilities*, 45 (3), 347-355. Accessed on October 30, 2013
8. 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
9. 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.
10. 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.
11. 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.
12. Miller M, Iosif AM, Young GS, Hill M, Phelps Hanzel E, Hutman T, Johnson S, Ozonoff S (2016): School-age outcomes of infants at risk for autism spectrum disorder. *Autism Res.* Jun; 9 (6):632-42. doi: 10.1002/aur.1572. Epub 2015 Oct 9.

Резиме**ГЛАВНИ ПОТРЕБИ И ПРЕДИЗВИЦИ НА РОДИТЕЛИТЕ
НА ДЕЦА СО АУТИСТИЧЕН СПЕКТАР НА НАРУШУВАЊЕ****Татјана Зорчец¹ и Нада Поп-Јорданова²**¹ Универзитетска клиника за детски болести, Скопје, РС Македонија² Македонска академија на науките и уметностите, Скопје, РС Македонија

Аутистичниот спектар на растројство (АСР) подразбира група комплексни, доживотни невноразвојни проблеми, кои се карактеризираат со симптоми поврзани со тешкотии во комуникацијата и интеракцијата со други луѓе, смален интерес и повторувачко поведение. Овие симптоми ја оневозможуваат способноста на заболениот да функционира правилно в училиште, на работа и во другите домени на животот.

За подобро разбирање на потребите и предизвиците на семејствата, изготвен е систематски анкетен лист во соработка на Аутизмот зборува и националните координатори за аутизам од девет земји. Целта на ова истражување е да се добие преглед на некои битни показатели за децата што страдаат од некоја форма на аутистично растројство.

Истиот прашалник е користен во два различни периоди (во 2015 г. и во почетокот на 2020 г.), вклучувајќи примероци од 60 и 140 семејства, соодветно.

Анкетниот лист содржи 57 прашања во следниве домени: демографски карактеристики, индекс на детските карактеристики, сервиси и перцепција на родителите/негувателите.

Добиените резултати се споредувани и дискутирани.

Овој преглед истакнува дека родителите и семејствата на децата со АСР во нашата земја имаат голем товар. Тие се соочуваат со значајни финансиски тешкотии и имаат потреба од подобри здравствени, едукативни и социјални служби. Заклучено е дека постои итна потреба од проширување на националните капацитети за грижа на децата, младите луѓе и возрасните со АСР, како и со други невноразвојни растројства.

Клучни зборови: аутистичен спектар на растројство, деца, анкета, потреби