

PERCEPTIONS ON SUPPORT, CHALLENGES AND NEEDS AMONG PARENTS OF CHILDREN WITH AUTISM: THE SERBIAN EXPERIENCE

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SUMMARY

Background: Autism spectrum disorders (ASD) significantly impact lives of affected individuals and their families. They confront daunting challenges and multiple demands in their daily life, when compared to parents of children with other disabilities or parents of typically developing children.

Subjects and methods: Participants completed The Caregiver Needs Survey, the survey intended for parents or primary caregivers of children with a diagnosis of ASD. During the study, 231 parents were interviewed; 167 mothers and 64 fathers. Parents were recruited from the patient database comprised of families from the two largest cities in Serbia. All of them were contacted before the study, either via phone or at the child's regular check-in visit.

Results: Over 90 percent of the parents reported that additional support at schools, home, and improved relationships with service providers are necessary and important. The most important challenges related to care were child's communication difficulties, social interaction difficulties, and problems with daily living skills. The significant predictors of lower overall satisfaction were parent's higher education, having a first concern related to problems of the child's interaction with others or playing alone, and parent frustration with accessing services in the past 12 months. Greater overall satisfaction, on the other hand, was related to having an in-school tutor training or assistance in managing child's needs or implementing treatments, and having primary care doctor or pediatrician as a source of information on autism.

Conclusions: Future efforts to develop ASD-related policies and services should also take the following into consideration: the low level of awareness among caregivers and health care providers about the early signs of autism; disparities in access to services; educational problems and significant levels of dissatisfaction with the overall care and stigma.

Key words: autism spectrum disorders – parenting – challenges – support – quality of life

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INTRODUCTION

Parents of children with ASD confront daunting challenges and multiple demands in their daily life, when compared to parents of children with other disabilities (e.g. Down syndrome) or parents of typically developing children. They frequently report higher level of stress, anxiety, depression and lack of social support (Rutgers & Ijzendoorn 2007, Woodman et al. 2014, Baker-Ericz et al. 2016, Golfenshtein et al. 2016). The nature and severity of these disorders may lead to increased levels of parental distress, with severe aggressive and self-injurious behaviors of children being the main contributors (Pozo et al. 2014). Furthermore, other symptoms related to ASD, such as the children's language and communication challenges cognitive impairment, and repetitive, self-stimulatory behavior have also been found to impact parental stress (Hoffman et al. 2009).

Noh et al. suggested that main concerns of parents of children with ASD are the child's lack of adaptability

(e.g., the child's inability to adjust to changes in the social environment), acceptability (e.g., the parent's perception of the child as less intelligent), and demandingness (e.g., the frequency and severity of the child's minor behavioral problems such as crying, disobeying, seeking attention) (Hoffman et al. 2009). Sharpley et al. found that the three most stressful factors associated with parenting a child with ASD in developed countries, are: (a) concern over the permanency of the condition; (b) poor acceptance of autistic behavior by society; and (c) very low levels of social support (Bitsika & Sharpley 2004). Families that receive different kinds of social support (e.g. support from family and friends, other families with similar problems, support from community programs, professional help, and the availability of services and programs tailored toward these families) may adapt easier to having a child with ASD (Siklos & Kerns 2006, Weiss et al. 2014). It has been reported that parents of ASD children often experience dissatisfaction with support provided by the community health and educational services (Bitterman et al. 2008), compared

to parents of children affected by other developmental disabilities (Siklos & Kerns 2006).

Most parents seek a range of supports to cope with the challenges of raising a child with ASD. These children often require extensive school support and community-based services throughout childhood (Bitterman et al. 2008). The lack of adequate training and programs in schools for teachers requires increased effort of parents in finding additional help. This leads to significantly more dissatisfaction and stress, mainly due to the inability to find adequate services that can provide proper education and care (Stoner & Angell 2006, Rattaz et al. 2014, Wei et al. 2014).

Stigma is one of the major problems experienced by ASD children and their families. It may be a result of many aspects of the disorders, but also stem from a lack of public awareness, knowledge, and perceptions of ASD (Gray 2002, Kinnear et al. 2016). Many authors have shown that parents frequently report feeling blamed for their child's behavior, isolated and excluded from the broader family and friends, having an overall feeling of distress and burden with a child's condition (Farrugia 2009, Kinnear et al. 2016, Stewart et al. 2017). Often times, most parents are confused with or find hard to manage the child's symptoms in the first years development and may avoid directly addressing these challenges. Avoidance has been demonstrated to be the most frequently used coping strategy for parents, and it correlates with the highest level of stress (Luong et al. 2011).

Serbia is located in Southeast Europe and it is considered a middle-income country according to World Bank criteria. The service system for children with disabilities in Serbia, including autism, covers laws, regulations, institutions and organizations that provide: possibilities of inclusion and proper education (individual educational plans, additional educational help, in-school tutors, as well as tutors outside school, special classrooms); financial aid for these families; additional education and training of healthcare and education providers; reduction of discrimination and abuse. (Mitic et al. 2011, Mihic et al. 2016). Despite these efforts, children with disabilities and their families in Serbia are very often exposed to financial problems and poverty, difficulties in finding and receiving adequate education and care, stigmatization by their community and surroundings, and different kinds of abuse and neglect (physical, psychical, sexual) (Mitic et al. 2011, Krstic et al. 2015, Mihic et al. 2016, Grujicic et al. 2016).

The aim of this study was to provide a comprehensive exploration of the support, challenges and needs among families affected by ASD in Serbia and to define family's overall satisfaction with the state of the support systems.

The study was conducted by the members of The Association for Child and Adolescent Psychiatry and Allied Professions of Serbia (DEAPS) in association

with Autism Speaks (AS) (www.autismspeaks.org) during 2016 and 2017. The Caregivers Needs Survey used in this study was developed by Amy Daniels and National Coordinators of The Southeast European Autism Network (SEAN), as a part of the Global Autism Public Health Initiative of AS. SEAN was founded to improve the lives of individuals with ASD and related mental health conditions in Southeast Europe. It commits to raising awareness, improving services, developing reliable public health data, and providing long term policy solutions. The Network was officially launched in Tirana, Albania in 2010, and consists of seven countries from southeast region of Europe: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Kosovo*, Macedonia, Montenegro and Slovenia. All of these participating countries are committed to raise the profile of autism as a social and public health priority not only in their country, but also in the region as a whole. To date this is the first study conducted in Serbia concerning the needs of the families of children affected with ASD.

*Kosovo's status as an independent country is disputed.

SUBJECTS AND METHODS

The Survey

The Caregiver Needs Survey consists of four sections: demographic characteristics; affected child characteristics; service encounters; and parent/caregiver perceptions. The majority of survey questions and responses were drawn from the existing population-based surveys on children with special health care needs, including ASD. The survey is intended for parents or primary caregivers of children with a diagnosis of ASD. It may be completed by parents via interview, in person, over the phone or online, and takes approximately 30 minutes to complete. These surveys included the following: the Interactive Autism Network's Child with ASD Questionnaire (IAN 2014); Survey of Pathways to Diagnosis and Services (CDC 2014); National Survey of Children with Special Health care Needs (CDC 2011); Affective subscale, Affiliate Stigma Scale (Mak & Cheung 2008); and the Support for Member with Disability, Family Quality of Life Survey (The Beach Center on Disability 2012).

To assess the perceptions of the overall satisfaction with support, as well as overall importance of support, two scales were created by adding up the scores on relevant items. Both scales showed acceptable/good reliability (Chronbach's alpha of 0.74 and 0.82, respectively).

Preparation of the Serbian version

After obtaining permission from the AS, the SEAN survey was translated from English into Serbian, independently by two researchers, and the translations were compared and combined. After this phase, back translation was performed by a third party, with the

result comparable to the original. Slight adaptation of wording was required due to the language sensitivity.

The ethics committee of the Institute of Mental Health in Belgrade approved the current study. All procedures were performed in accordance with the committees' guidelines and regulations. The study was conducted between December 2016 and March 2017.

Procedure

Parents were recruited from the patient database comprised of families from the two largest cities in Serbia. All of them were contacted before the study, either via phone or at the child's regular check-in visit. All parents signed the consent form and were given

information regarding the survey. A part of them were interviewed over the phone upon their acceptance of participation, while others were interviewed during the child's visit.

Participants

During the study, 231 parents were interviewed; 167 mothers and 64 fathers. The average age of the child in the moment of parental interview was 10.5 years (SD 5.8). The majority of parents (57.1%) finished primary and secondary school, and over 40% of parents had higher than secondary school education level. This study was approved by the Ethics Committee; all of the participants in the study gave informed consent.

Table 1. Parent and child general and autism-related characteristics

Characteristics	N	valid %	X	SD
Parent				
Father	64	27.7		
Mother	167	72.3		
Parent education				
Primary and secondary school	132	57.1		
Attending / completing university or postgraduate degree	99	42.9		
Child's gender				
Male	183	79.2		
Female	48	20.8		
Child's current age (months)			126.05	69.6
Child's current verbal ability				
Does not talk, or uses single words only, or 2 or 3 – word phrases	180	77.9		
Uses sentences with 4 or more words, or complex sentences	51	22.1		
First concerns				
Medical problems (seizures, growth, stomach)	53	23.2		
Behavioral problems (sleeping, eating, high activity, tantrums, wandering, aggressiveness)	151	65.7		
Didn't make eye contact when talking or playing with others	175	76.4		
Didn't respond when called or didn't respond to sound	165	71.7		
Problems of nonverbal communication	167	72.9		
Talked later than usual for most children	129	57.6		
Was not talking at all	77	33.5		
Did not talk as well as other children that were the same age	148	65.8		
Some speech skills that he/she had already developed were lost	108	48.2		
Didn't seem to understand what parents or others said to him/her	179	78.5		
Problems with coordination or gross motor skills	57	25.0		
Problems with fine motor skills	167	72.9		
Problems of interacting with others / playing alone	203	88.6		
Problems with change / insisting on sameness	154	67.8		
Difficulties learning new skills (i.e. toilet, getting dressed)	154	67.5		
Difficulties learning new things (i.e. letters and numbers)	152	67		
Unusual gestures or movements	183	80.6		
This parent was the first to have concern about the child development	149	64.5		
Child's age when first concerns were perceived (months)			22.50	10.5
Child's age at diagnosis (months)			45.80	22.4
Home distance from services where diagnose was established				
More than 100 km	47	20.8		

Table 2. Services, information sources and stigma among participants

Characteristics	N	valid %
Treatments used ever		
Standard developmental non-pharmacological treatments (behavioral, sensory integration therapy, cognitive based therapy, occupational therapy, physical therapy, social skills training, speech or language therapy)	203	89.0
Psychotropic medication	118	52.4
Other (horseback riding, homeopathy, or food supplements such as carnosine)	34	18.8
School enrollment		
Inclusion (preschool, regular public or private school)	87	38.2
No inclusion (special school for children with disabilities, home-schooled, not enrolled in school)	141	61.8
Additional academic support		
Special classrooms for children with autism	35	16.7
Special classrooms for children with disability	59	28.1
In-school tutor	18	8.6
In-school aide/shadow	24	11.4
Tutor outside school	11	5.3
Other services		
Training or assistance in managing child's needs /implementing treatments	54	24.1
Special government assistance for child with autism	163	71.8
Participating in family support / advocacy groups or organization	65	28.9
Parent's typical sources of information on autism		
The Internet	174	76.3
Child's primary care doctor / pediatrician	87	38.5
Child's teacher	105	46.7
Other parents of children with autism	174	76.7
Other treatment providers who work with child (i.e. health specialists, therapists)	162	71.1
How often has the parent been frustrated in efforts to get services for the child in the past 12 months		
Never, sometimes	138	60.3
Usually, always	82	35.8
Don't know	9	3.9
Child's autism caused financial problems in the family	162	70.4
Stigma		
I feel helpless for having a child with autism	78	34.1
I worry if other people know I have a child with autism	11	4.8
Other people would discriminate against me because I have a child with autism	70	30.4
Having a child with autism imposes a negative impact on me	65	28.3

Statistical analysis

The descriptive data were presented through frequencies, percentage, means and standard deviations. To identify the potential predictors of the overall satisfaction with support, we first conducted the series of bivariate analysis with all presented variables (t-test, Pearson's or Spearman's correlation depending on the parametric properties of the variables). We then conducted a multiple linear regression model of the overall satisfaction with support as outcome, with its significant bivariate correlates as predictors.

RESULTS

Demographic characteristics of the caregivers and children as well ASD-related characteristics are presented in Table 1. The children with ASD were mostly males, dominantly not speaking any sentences that

include 4 or more words. The top three first concerns related to autism were: 1) problems of interacting with others or playing alone; 2) unusual gestures or movements; and 3) child not understanding what parents or other adults said to him/her. Almost two thirds of the parents were the first ones to recognize that something was wrong with the development of the child, and over 20 % of families traveled more than 100 km to get diagnosis (Table 1).

Data on use of medical and additional services, sources of information for families, and stigma are presented in Table 2. Most of the parents responded that their child had some form of standard developmental non-pharmacological treatment during the child's lifetime, whereas about half of them reported having pharmacotherapy at some point. Other kinds of therapy (such as horseback riding, homeopathy, or food supplements such as carnosine) were present in less than 20% of the cases. Almost 40% of children were enrolled in

regular pre-school or school (inclusion). The most frequently reported form of additional academic support was special classroom for children with autism or for children with disability (over 40%). Training or assistance in managing child's needs or implementing treatments was present in almost 25% of cases. Over two thirds reported receiving special government assistance for their child with autism, and close to 30% participated in family support groups or organizations. The most prominent sources of information for families were the Internet and other parents of children with autism, closely followed by other providers such as health specialists and therapists who work with the child. In contrast, primary care doctors or pediatricians were the least frequently endorsed sources of informa-

tion for families. About one third of parents reported being frustrated in efforts to obtain services for their child in the past 12 months, and had some feelings of stigma (e.g., helplessness, discrimination) (Table 2).

Perceptions of importance of and satisfaction with various kinds of support are presented in Table 3. Over 90% of parents reported that support to make progress in school, at home, to make friends, and having a good relationship with the services providers are important, with more or less a two third believing these forms of support are very important. When it comes to satisfaction with these forms of support, about half of the parents were neutral, while the number of parents who felt very satisfied was mostly higher comparing to those who felt very dissatisfied (Table 3).

Table 3. Parent perceptions on support - importance and satisfaction

Parent perceptions on support	N (valid %)		
	A little important	Important	Very important
For a family to have a good life together, how important is...			
...that my child with autism has support to make progress in school?	13 (5.7)	61 (26.5)	156 (67.8)
...that my child with autism has support to make progress at home?	3 (1.3)	81 (35.2)	146 (63.2)
...that my child with autism has support to make friends?	17 (7.5)	74 (32.5)	137 (60.1)
...that my family has a good relationship with the services providers who work with my child?	11 (4.8)	56 (24.3)	163 (70.9)
	Very dissatisfied	Neutral	Very satisfied
How satisfied am I ...			
...that my child with autism has support to make progress in school?	40 (17.9)	120 (53.6)	64 (28.6)
...that my child with autism has support to make progress at home?	38 (16.7)	105 (46.1)	85 (37.3)
...that my child with autism has support to make friends?	52 (22.8)	123 (53.9)	53 (23.2)
...that my family has a good relationship with the services providers who work with my child?	42 (18.2)	134 (58.0)	55 (23.8)

Table 4. Multiple linear regression model of overall satisfaction with support

Predictors (variables with significant bivariate associations with the outcome)	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	p
Didn't respond when called or didn't respond to sound	-0.504	0.339	-0.107	-1.486	0.139
Problems of nonverbal communication	0.052	0.385	0.011	0.135	0.893
Didn't seem to understand what parents or other adults said to him/her	0.065	0.394	0.012	0.165	0.869
<i>Problems of interacting with others / playing alone</i>	<i>-0.946</i>	<i>0.462</i>	<i>-0.137</i>	<i>-2.048</i>	<i>0.042</i>
Difficulties learning new skills	-0.125	0.313	-0.028	-0.399	0.690
<i>In-school tutor</i>	<i>0.928</i>	<i>0.453</i>	<i>0.131</i>	<i>2.048</i>	<i>0.042</i>
<i>Training or assistance in managing child's needs /implementing treatments</i>	<i>0.652</i>	<i>0.298</i>	<i>0.137</i>	<i>2.188</i>	<i>0.030</i>
<i>Primary care doctor / pediatrician as information source</i>	<i>0.999</i>	<i>0.264</i>	<i>0.239</i>	<i>3.779</i>	<i>0.000</i>
Child's autism caused financial / work impact on the family	-0.170	0.217	-0.050	-0.784	0.434
<i>Education (beyond secondary school)</i>	<i>-0.978</i>	<i>0.263</i>	<i>-0.237</i>	<i>-3.722</i>	<i>0.000</i>
<i>How often has the parent been frustrated in efforts to get services for the child in the past 12 months (usually / always)</i>	<i>-1.213</i>	<i>0.286</i>	<i>-0.288</i>	<i>-4.242</i>	<i>0.000</i>
Feeling helpless for having a child with autism	-0.356	0.278	-0.082	-1.277	0.203
Feeling that other people would discriminate him/her for having a child with autism	-0.081	0.289	-0.018	-0.281	0.779

To identify the potential predictors of the overall satisfaction with support, we first conducted bivariate analyses with the variables from Table 1 and Table 2, as well as with the scale of the overall importance of support, resulting in several significant associations. Namely, lower scores on the overall satisfaction with support were associated with the presence of several first concerns – not responding when called or to sound ($t=-3.624$, $p=0.000$), problems of nonverbal communication ($t=-2.152$, $p=0.032$), not understanding what parents or other adults said to him/her ($t=-2.286$, $p=0.023$), problems of interacting with others or playing alone ($t=-3.922$, $p=0.000$), and difficulties in learning new skills ($t=-2.906$, $p=0.004$). Furthermore, lower overall satisfaction was also related to parent’s greater education (beyond secondary school) ($t=-3.562$, $p=0.000$), having financial problems due to autism ($t=-3.165$, $p=0.002$), being frustrated with access to services in the past 12 months (usually / always) ($t=-6.642$, $p=0.000$), as well as feeling helpless ($t=-3.332$, $p=0.001$) and discriminated ($t=-2.053$, $p=0.041$). Greater overall satisfaction, on the other hand, was related to having an in-school tutor ($t=2.338$, $p=0.020$), training or assistance in managing child’s needs or implementing treatments ($t=2.598$, $p=0.010$), and having primary care doctor or pediatrician as a source of information on autism ($t=3.830$, $p=0.000$).

We then conducted a multiple linear regression of the overall satisfaction with support as an outcome, and

its bivariate significant correlates as predictors. The model was significant ($F=7.774$, $p=0.000$), explaining about the third of the variance of the satisfaction with support (Adjusted R Square=0.324). After controlling for relative effects, the significant predictors of lower overall satisfaction with support were parent’s higher education, having a first concern related to problems of interacting with others or playing alone, and the parent being frustrated with access to services in the past 12 months. Factors associated with greater satisfaction, in contrast, were having an in-school tutor, receiving training or assistance in managing child’s needs or implementing treatments, and having a primary care doctor or pediatrician as an information source (Table 4).

Finally, the main challenges related to the care of a child with autism and to getting the support for the child with autism, as well as the main priorities for families affected by autism in the country is presented graphically. The top three challenges related to care were a child having communication difficulties, social interaction difficulties, and problems with daily living skills (Figure 1). The top three challenges that parents face in getting the support for the child referred to education, welfare/social supports, and health care (Figure 1). Lastly, the three main priorities for families affected by autism in the country, as identified by the parents, were having greater rights for individuals with autism, improved health care services, as well as improved welfare/social services (Figure 2).

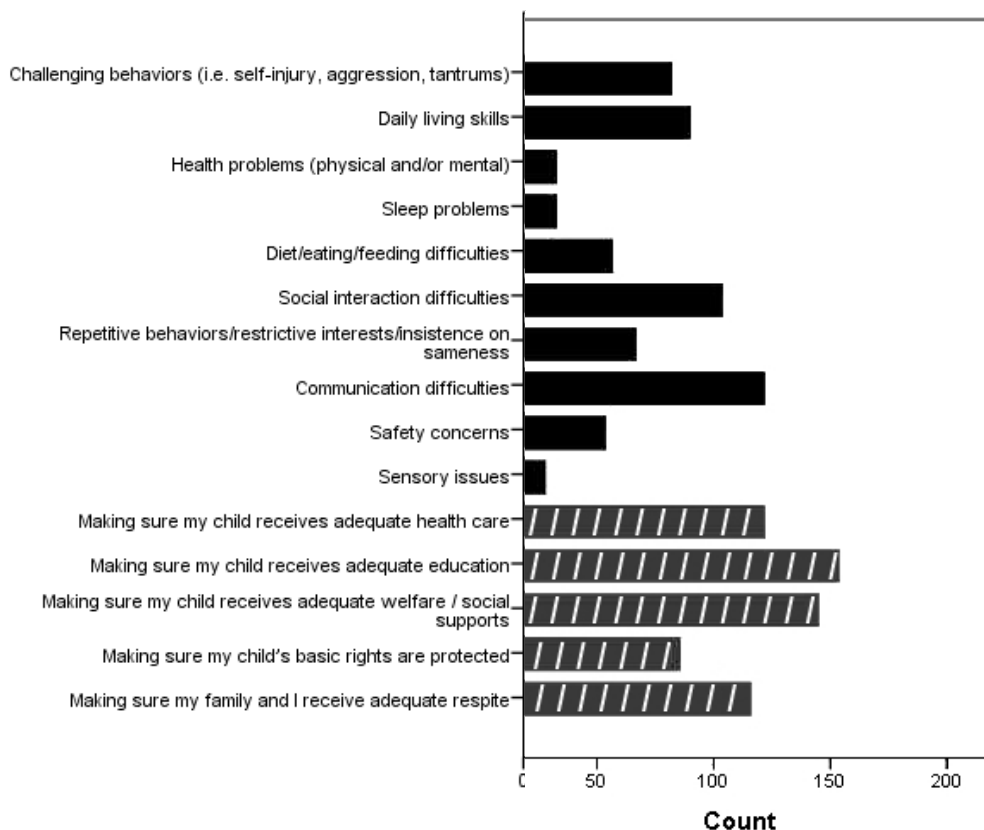


Figure 1. Main challenges in caring for a child with autism, and in getting support for the child
 Black bars – caring difficulties; Black and white bars – support difficulties

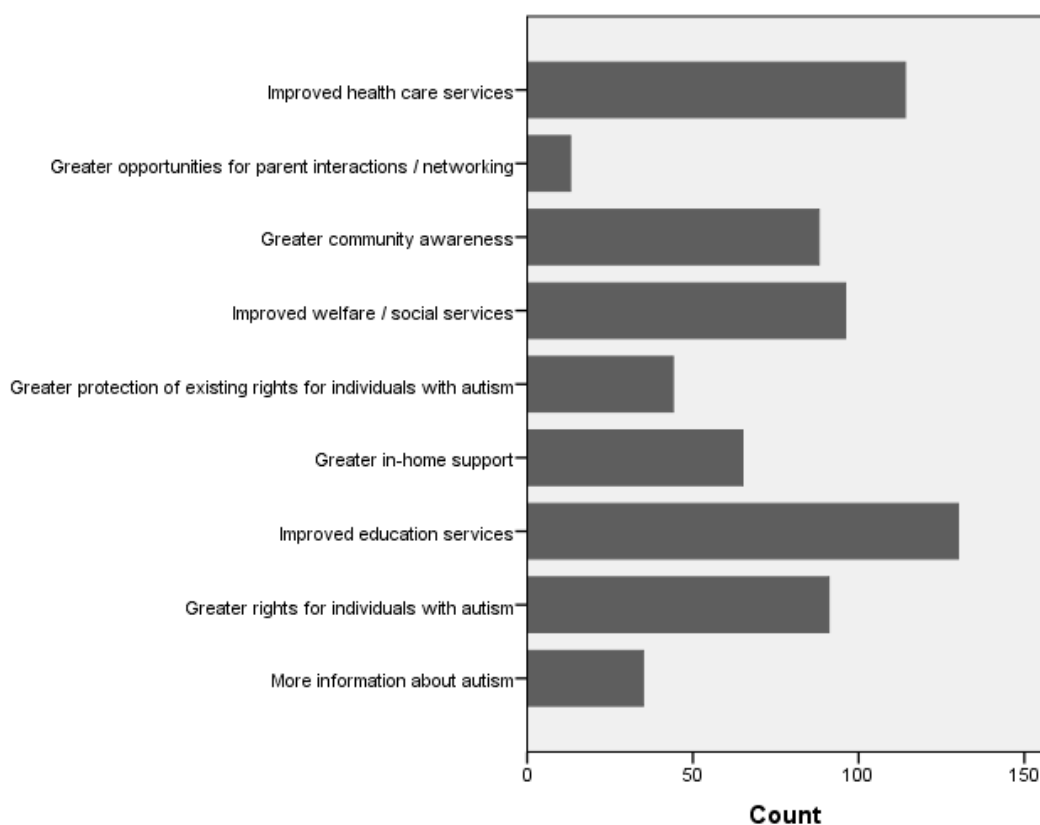


Figure 2. Main priorities for families affected by autism in the country

DISCUSSION

It has been well documented that a higher prevalence of ASD is found among male children, and data in our study are similar; nearly 80 percent of children were boys (Christensen et al. 2016). In our study, mean age for final diagnosis of ASD was 45.8 months (SD=22.4), but first concerns expressed by parents appeared much earlier- the average age was 22.5 months (SD=10.5). A significant amount of evidence shows that a reliable and stable diagnosis of ASD can be made around the age of two years (Boorstein et al. 2008, Martínez-Pedraza & Carter 2009).

Detection and explanation of symptoms can be significantly delayed by their parents or/and physicians (Werner et al. 2005, Ozonoff et al. 2010). This time lag from the occurrence of the first symptoms and the diagnosis may be due to lack of access to diagnostic or evaluation services; our results show that over 20 percent of parents had to travel more than 100 km to receive a valid diagnosis and care for their children. In standard practice in Serbia there is no regular screening or proper prospective assessment of children at risk of developmental disorders, and detection of these problems often relies on parents expressing concerns to physicians.

The majority of interviewed caregivers in our study were mothers. This finding was expected because mothers are the ones that more frequently care for chil-

dren's health, educational and emotional needs, and they are commonly full time occupied as stay-at-home parents, whereas fathers are more interested in playing a role of main financial providers (Dokmanovic 2016). Slightly more than a half of the parents in our study primary or secondary educational levels, while in some countries it has been reported that children with ASD had more educated parents than the general population (Kogan & Blumberg 2007, Zuckerman et al. 2015). In several studies parents with lower education experience significantly more stress and have less access to services, less knowledge of typical child development, which consequently leads to later diagnosis of ASD (Kogan & Blumberg 2007, Reavis et al. 2007).

The most frequently expressed first concerns in our study were the problems of interacting with others or playing alone, unusual gestures or movements, and child not understanding what parents or other adults said to him/her. To some extent these findings are consistent with the most commonly reported first concerns by parents (Landa & Garrett-Mayer 2006, Zuckerman et al. 2015, Herlihy et al. 2015). At the same time, parents show the lowest first concern for medical problems (23%), coordination problems and gross motor skills (25%), as well as lack of speech in general (33%), which can also be explained by previous understandings.

Nearly ninety percent of questioned parents reported that they used some kind of standard developmental non-pharmacological treatment for their children at

some time since receiving the diagnosis. These treatments include behavioral therapy, sensory integration therapy, cognitive based therapy, occupational therapy, physical therapy, social skills training, and speech or language therapy. A very small number of experts are present in Serbia with formal education for applied behavioral analysis, sensory integration and training of social skills. Over half of parents said that their children with ASD were using some kind of psychotropic medication during life, which is consistent with findings of other studies (Altiere et al. 2009, Defilippis & Wagner 2016).

Almost two thirds of children in Serbia are not included in regular classrooms. They are most frequently using special classrooms for children with disabilities; this is the type of service that educational system in Serbia still offers to children with any kind of disabilities. However, there has been an increasing trend to include children with autism and other disabilities in the general education classrooms, along with their typically developing peers (Harrower & Dunlap 2001, Kasari et al. 2007). This was recognized to be a beneficial change for ASD individuals, especially with regards to their social skills (Simpson & Boer-Ott 2003, Belini et al. 2007).

The majority of interviewed parents receive special government assistance for their child, mostly as financial help. This is very beneficial for these parents, because it has been shown that they usually report financial problems due to high out-of-pocket health care expenses, underemployment or employment loss (Kuhlthau 2015). A large number of our responders had financial difficulties, most likely due to lack of healthcare centers near their hometown, and a need to individually financially provide for additional care, such as speech, cognitive, social skills therapy, and even medication and educational services (special classrooms, tutors).

More than one third of parents in our study were usually/always frustrated in efforts to get services for their child. The lack of information about the condition, prevention and treatment provided by health services (Liptak et al. 2006), and lack of capacities of schools to address the child's needs are the most commonly reported causes of frustration (Bitsika & Sharpley 2004, Prelock & Hutchins 2008). This can be the reason parents were primarily informed over the internet or from other parents that have a child with autism (over 70 percent of our sample). Ironically, parents who sought information from pediatricians and primary care physicians – only a small minority in this study, were those who reported greater overall satisfaction. We assume that this was the case because they were professionals, and with them parents had greater trust.

Parents of children with ASD are predisposed to be stigmatized and isolated from their social surroundings (Russel & Norwich 2012), and this is consistent with

our study, which may be due to low general awareness or knowledge about these types of disorders in Serbia. One of the factors that significantly reduce stress in ASD parents (mainly in mothers) is social support (Bitsika & Sharpley 2004). Parents are looking for a formal social support in caring for their child, such as medical doctors, psychologists, social workers, teachers, and later they tend to search for some other kind of informational support from family outside their home, friends, other parents, and support groups (Altiere & Kluge 2009). Inability to find such support can lead to increased levels of anxiety, isolation, poverty, as well as signs of clinical depression (Bitsika & Sharpley 2004, Luong et al. 2009). In this study, when asked about the importance of support and relationship that they have with different support services, more than two thirds of parents answered that it is very important for their child's welfare, but about 20 percent of them were very dissatisfied, and about half of the parents were neither satisfied nor dissatisfied. It is well documented that parents who have children with developmental disabilities are frequently dissatisfied with health care and school and educational systems (Siklos & Kerns 2006, Bitterman et al. 2008, Baghdadli et al. 2014). It has also been shown that parents of children with ASD are more experience greater stress related to obtaining adequate care for their children, compared to parents of children with other physical or mental disabilities (Gray 2002, Huang & Newacheck 2004, Stoner & Angell 2006, Liptak et al. 2006, Petrina et al. 2015).

The significant independent risk factors for the overall dissatisfaction in our study were parent's higher education, having a first concern related to problems of interacting with others or playing alone, and the parent being frustrated with access to services in the past 12 months. The protective factors, on the other hand, were having an in-school tutor (personal assistant), training or assistance in managing child's needs or implementing treatments, and having a primary care doctor or pediatrician as an information source. This is in accordance with studies showing that child's behavioral problems (Hartley et al. 2012), lack of social support (Ekas et al. 2015), higher levels of parental education (Chiu et al. 2014), lack of child's adaptive skills (McCarthy et al. 2006), and lack of adequate health and educational services (Rattaz et al. 2014) are some of the well-established dissatisfaction predictive factors.

The main challenges for the parents were receiving adequate healthcare, education and social support, suggesting that Serbia should prioritize improving these services and raising overall community awareness. These challenges and priorities identified by parents in Serbia are not very different from those reported in other counties where health and educational services are also prioritized (Bitterman et al. 2008, Pituch et al. 2011, Russel & Norwich 2012, Rattaz et al. 2014).

Although the current study presents many innovative findings in our country, the results should be evaluated in the context of several limitations. First of all, the group of parents was rather small and it was mostly composed of mothers. While parents are generally valid reporters of their child's health care quality and experiences, some reports may be a reflection of their satisfaction of their child's healthcare overall, rather than specific actions that the provider took or failed to take in response to their concerns. Second, the data were collected from parents whose children are registered and treated at two major autism treatment centers. The sample does not represent children with ASD who are treated in community settings; both healthcare centers in which we conducted our study were placed in two of the largest cities in Serbia and families were mainly living in urban surroundings with higher education and higher income. These families were already included in the treatment process, most of them being cooperative, well informed about their child's condition, and highly motivated to provide care for their child. We assume that there are many other families living in rural surroundings impacted by ASD, with larger socio-economic problems and demands, and these results may not be generalized to the whole population. In future, enlargement of the sample with these families would likely produce a more comprehensive picture of challenges that families with ASD face in our country.

CONCLUSIONS

Future efforts to develop ASD-related policies and services in Serbia should take these study results into consideration. The proposed steps include: raising the overall level of awareness among caregivers and healthcare providers about the early signs of autism, overcoming disparities in the access to services and improving techniques to address educational challenges of children with ASD. A special emphasis should be made to address parental satisfaction and stigma. According to Serbian laws (healthcare law, social security law, education law), the country has well planned strategies and regulations for providing help and support for families impacted by children with developmental disabilities. Parents that participated in our study were mostly well aware of these regulations; parental associations are well organized and are promptly and continuously helping each other. However, results of this study demonstrate that regulations and policies are just one side of a coin, and that raising awareness among decision-makers along with continuous advocacy is crucial to the improvement of the family position. It is obvious from our research that having a good law is only one small piece in the care for children and families; the majority of these strategies and laws were unsuccessfully implemented due to lack of human and organizational resources, as well as the economic state of the country.

Successfully enhancing awareness, improving services, and developing long-term policy solutions would be only possible with comprehensive understanding of the needs and challenges faced by families affected with ASD. These actions could significantly raise the overall life quality and reduce stress and dissatisfaction among children affected with ASD and their families, not only in Serbia but worldwide.

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Contribution of individual authors:

Milica Pejovic-Milovancevic was leading contributor to the design and analysis of this study and wrote the manuscript;

Miodrag Stankovic was second leading contributors to the design and wrote the manuscript;

Marija Mitkovic-Voncina was contributing to the analysis of this study;

Nenad Rudic, Roberto Grujicic, Alexia S. Herrera, Aleksandra Stojanovic & Bojan Nedovic were contributor to the data collecting;

Andy Shih was contributing to the study design;

Vanja Mandic-Maravic was contributing to the analysis of this study;

Amy Daniels was contributing to text writing.

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