



■ Professor Milica Pejovic Milovancevic, MD, PhD
Clinical assistant Vanja Mandic Maravic, MD, PhD
Milica Vlasisavljevic, MD
Sanja Lestarcic, MD
Jelena Vasic, MD

STATUS OF SUPPORT AVAILABLE TO YOUNG PEOPLE WITH AUTISM SPECTRUM DISORDERS (ASD) AND THEIR FAMILIES



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CONTENTS

Executive summary	6
Background	7
Definition	7
Clinical characteristics	8
Epidemiology	8
Comorbidities and behavioural difficulties in ASD	9
Impact on children, youth and families	10
Persons with ASD - the significance of adequate support	11
Aim	12
Method	13
Questionnaire	13
Study participants and procedure	13
Sample	13
Statistical analysis	13
Results	14
Experience with services	19
Parent/caregiver perceptions	24
Discussion	31
The access to healthcare system	31
Meeting support needs	31
Information provision	32
Support systems	32
Inclusion in education system and transition planning	32
Social support	34
Community-based support	35
Conclusions and Recommendations	36
References	38

EXECUTIVE SUMMARY

PURPOSE OF THE STUDY

Mapping available support services for young people with ASD and their families, assessing their greatest needs and examining the perception and attitudes of the parents/caregivers towards the existing support system.

METHODOLOGY

Parents/caregivers of adolescents and young adults with ASD – from 15 to 30 years of age were recruited from the database of Institute of Mental Health and surveyed using an adapted version of The Caregiver Needs Survey (SEAN).

MAIN CONCLUSIONS

- Only a minority of parents reported receiving education on their children's needs. Parents pointed out lack of information and long waiting lists as the most important barriers in accessing services.
- The majority of parents reported socio-economic adversities – financial difficulties, quitting work or working part-time due to increased parenting demands.
- The majority of parents denied feeling concerned that other people would find about their child's diagnosis or experiencing discrimination.
- Over 90% of parents/caregivers stated that good collaboration with services involved in care for children with ASD, as well as support at home, at school and in making friends are important.
- The greatest challenge was reported to be getting adequate healthcare for their children, followed by protection of child's rights and getting adequate education.
- The majority of parents highly prioritize the development and enhancement of healthcare services, education, social services, as well as improving children's and young people with autism's rights.

RECOMMENDATIONS

Our data suggest that improving communication with services and information providers is of great importance, together with improving accessibility of the healthcare and educational system for persons with autism.

Involving parents and providing them with support remains one of the top priorities.

BACKGROUND

Children with autism spectrum disorders (ASD) are one of the most vulnerable groups, who have difficulties in accessing the appropriate services and they rarely achieve or maintain a satisfactory level of development and health.

Without additional support in the areas of health care, rehabilitation, social protection, education and pedagogy, and growing up in the family environment, the development and health of these children can be seriously threatened, and they belong to the group of children with physical and developmental disabilities (Veljković, 2018).

The UN resolution, which focuses on the socioeconomic needs of individuals, families and societies associated with ASD and other developmental and physical disabilities (adopted in 2014), points to the rights of persons with ASD, but also to the obligations of the Member States, and particularly highlights:

- developmental disabilities and difficulties and early identification of autism symptoms must be recognized in all policies and programmes related to development of children in the earliest childhood;
- policies and programmes, as well as the adequate regulation and multisectoral plans, must be developed; they shall include public awareness and stigma removal campaigns, and shall be supported with the sufficient human, financial and professional resources;
- strategies for early identification and community interventions for children with ASD and other

developmental disabilities and difficulties must be developed;

- adequate infrastructure must be developed for joint approach, including education, child care, support, intervention, services and rehabilitation of children with ASD and other developmental disabilities and difficulties;
- social and psychological assistance must be provided to families whose members have disabilities and difficulties;
- the importance of research and implementation of evidence-based interventions is promoted in all sectors;
- inclusive education programmes tailored to young children and people with autism must be strengthened;
- expertise and the joint evidence-based approach to interventions must be developed (Smythe et al, 2021).

The United Nations General Assembly also recognized developmental disabilities and difficulties, and particularly ASD, in 2007, through the Declaration on establishing 2 April as the World Autism Awareness Day.

Definition

Autism spectrum disorder (ASD) refers to a neurodevelopmental disorder defined by a number of behavioral features. Core clinical characteristics of ASD include impairments in social communication and social interaction, as well as restricted, repetitive patterns of behavior, interests or activities (American Psychiatric Association, 2013).

These symptoms are present in the early developmental period, but may not be fully manifest until social demands exceed the child's capacities, or may be masked by learned strategies in later life. International classification (ICD-10) classifies autism under pervasive developmental disorders, characterized by qualitative abnormalities in reciprocal social interaction, idiosyncratic patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities (World Health Organization, 1993). New edition of the same classification ICD-11 incorporates some modifications: difficulties in interaction and social communication on the one hand, and restricted interests and repetitive behaviours on the other. It no longer includes difficulties related to language (World Health Organization, 2019).

Clinical characteristics

Impairment in social interaction and communication is considered to be the most prominent core feature of ASD.

This includes impairment in non-verbal behaviors used to regulate social interactions, failure to develop appropriate peer relationships, and lack of spontaneous seeking to share enjoyment, interests or achievements with others. Children with ASD also exhibit stimulus over selectivity, impairment in joint attention and theory of mind impairments (Happé, 2006; Baron-Cohen, 2009). Nonverbal behavior is used significantly less than in typically developing children. These impairments cause lack in social or emotional reciprocity. Even high-functioning persons with ASD have problems in peer relations. Problems in peer relations include lack of interest, problems in interpreting other's actions and responding accordingly.

Language development is impaired in children with ASD. The rate, volume and intonation of speech can be specific, and echolalia is frequent (Rey, 2019).

Epidemiology

The ASD prevalence in many low- and middle-income countries has been unknown so far, and the World Health Organization (WHO) estimates that 1 in 100 children in the world have ASD. This estimate represents the average value, and some well-controlled studies are estimating the higher prevalence (Zeidan, 2022). The lack of records in most countries, especially those with low or medium income, points to the need of harmonizing the criteria for diagnosing and the research methodologies (Zeidan, 2022; Chiarotti, 2020).

Based on the epidemiological studies conducted over the past 50 years, the ASD prevalence appears to be increasing globally.

There are many possible explanations for this evident increase, including the increase of awareness and knowledge, expansion of diagnostic criteria, improvement of diagnostic instruments (tools) and better reporting. The increase in prevalence is also the consequence of the fact that recent studies have covered the entire populations, but the true incidence increase also cannot be excluded (Zeidan, 2022). 33% of the increase in the ASD prevalence can be explained by the change in the diagnostic criteria, 42% by including the outpatient contacts with health care institutions, and almost 60% of the prevalence increase can be explained by the combination of these two changes in the way ASD is registered (Hansen, 2015).

According to the recently completed Census 2022, Serbia has the population of 6,690,887 people, and a detailed demographic profile of the country is yet to be published. Based on population estimates in 2021, children aged 0-18 make up 18.4%, and the number of children with disabilities and developmental disabilities is unknown (Procene stanovništva, 2020).

According to the 2011 Census, children with disabilities and developmental disabilities make up about 0.7% of the total child population, while the generally accepted estimate is that children with disabilities and developmental disabilities make up 5% of the child population,

which was confirmed by the latest MICS6 (Multiple Indicator Cluster Survey) by research in Serbia (Marković, 2011; Hansen, 2015).

The register of children with developmental disabilities (ages 0-5) began recording applications in mid-2022. In two months, 207 children under the age of five were registered with F84 - Pervasive developmental disorders, that is, every sixth child in the Registry has this diagnosis.

The average age of persons with disabilities obtained through the census is ten years higher than the average age of persons with disabilities from the countries of the region, so these results cannot be taken as representative for children with developmental disabilities and difficulties. The target population of this study is persons aged 15-30. The data on disability status or prevalence of ASD in this population is not available, and it would be of utmost significance to add data about young people with disabilities in Serbia.

Data from the research on the territory of Serbia indicates that, on average, two years pass from the first concern of the parents to the diagnosis of ASD (Pejovic-Milovancevic, 2018). In order to collect the data on the number and functionality of children and youth with ASD, it is necessary to introduce a unified database, i.e. a registry, which is certainly one of the tasks for professionals in the future.

Comorbidities and behavioural difficulties in ASD

Persons with ASD are more likely to have other mental disorders compared to the general population.

Among various co-occurring medical conditions, the issue of psychiatric comorbidity has become more relevant in recent years. It has been shown that, in addition to psychiatric co-morbidities being more common, the

severity of clinical symptomatology is often more severe (Romero, 2016).

It is estimated that almost 70% of people with ASD have at least one, and 40% have two or more co-morbid psychiatric disorders (Hossain, 2020).

Previous studies have shown that psychiatric comorbidity in ASD significantly increases difficulties in adaptation, affects daily activities, reduces quality of life and emphasizes problems such as restlessness, passivity, social isolation, aggressiveness, irritability or self-injury (Lai, 2019). Diagnosing psychiatric co-morbidities can be challenging with recognition difficulties present within a complex condition such as ASD, especially as symptoms may be masked due to communication difficulties (Huerta, 2012).

Certain genetic disorders are more common in this population group such as fragile X syndrome, neurofibromatosis type I and tuberous sclerosis. Children with ASD are also more prone to various neurological disorders, including epilepsy (in almost a third), macrocephaly, hydrocephalus, cerebral palsy, migraines/headaches and congenital abnormalities of the nervous system. Sleep disorders are also a significant problem, which occur in 80% of cases and are closely related to behavioral problems, learning difficulties and a reduction in the overall quality of life. Gastrointestinal disorders are evidently more common than in the general population and occur in 46% to 84% of cases. A more frequent presence of allergic, metabolic and immune disorders was observed in all age groups (Al-Beltagi, 2021; Lindor, 2019).

In more than 50% of persons with ASD, aggressive behaviour can be observed. This group of symptoms in ASD include hetero-aggressive behaviour, auto-aggressive behaviour, hyperactivity, anxiety, withdrawal, oppositional defiant disorder and impulsivity (Lindor, 2019).

Impact on children, youth and families

Early identification of symptoms specific for ASD and diagnosing in a timely manner is a challenge and implies the responsibility of professionals to conduct specific procedures as early in life as possible in order to provide timely interventions. At this age, parents are the most important support for the child's development and life. Therefore, taking care of the child's development also involves taking care of parents and parenting all the time.

On the other hand, confronting a family with a suspected ASD, and then with the diagnosis, its chronicity, and the still insufficiently numerous and developed services for provision of support at the earliest age, requires the involvement of a number of professionals from different fields (paediatricians, psychologists, special education teachers, preschool/school teachers, pedagogists, professional teams for inclusive education in schools, therapists and other persons trained to work with children with ASD and their families, social workers, child psychiatrists and others) with the possibility of coordinated work.

Multidisciplinary and multisectoral approach to these children, young people, and their families will enable families to get a timelier and better help.

This approach is extremely important given the fact that interventions for children and young people with ASD focus primarily on increasing their functionality, i.e. improving their life skills and equal participation in the family, leisure activities, kindergarten and school and society as a whole. The care for the child therefore includes the care for his or her education and exercise of all other rights, which, inter alia, also relate to protection against discrimination, which is very prominent in our society (Veljković, 2018).

As it is shown, the core symptoms of ASD can cause significant impairment, which can be even more severe

with concurrent behavioural disorders and psychiatric and physical comorbidities. Studies have shown that mean health-related quality of life of children with autism were significantly lower compared to healthy population, while significantly worse total, psychosocial, emotional and social functioning have been demonstrated in children with autism compared to population of children with other chronic medical conditions (Kuhlthau, 2009). Lower quality of life in comparison to neurotypical peers appears to persist into adolescence and adulthood (Skaletski, 2021).

The quality of life of the children with ASD is postulated to differ according to specific autistic traits that are present, as well as to individual executive functioning (de Vries, 2015). However, even adolescents with high functioning ASD report significantly lower levels of satisfaction with their friendships, leisure time, affective and sexual relationships (Cottenceau, 2012), along with more prominent difficulties in executive functioning and emotion processing, compared to typically developing adolescents (Dijkhuis, 2016). Some authors challenge the quality of life research framework, seen as a measure of one-dimensional outcome domains – psychiatric functioning, academic achievements, living and working conditions etc. and emphasize the need to tailor other frameworks to conceptualize a good outcome for the persons with ASD (Billstedt, 2010).

Although improvements in healthcare increased the potential of the persons with ASD, still most of these patients never become completely independent or work full-time (Lord, 2018).

The small proportion of individuals with ASD in skilled and professional positions raises concern, since unemployment, poverty and the inability to live independently all increase social isolation, hindering the development of intimate relationships and close friendships (Howlin, 2013). Premature mortality is increased in persons with ASD, primarily in the presence of comorbidities or intellectual disability (Hirvikoski, 2016; Schendel, 2016).

Research suggests that parents of the children with ASD have high levels of stress, along with lower quality of life Ni'matuzahron, 2021.

The physical and psychological health of the caregivers appears to be negatively impacted by raising a child with ASD, while their social relations appear to be impaired (Turnage, 2022). Lower quality of life of the caregiver appears to correlate with the frequency of the disruptive behavior of the child, as well as the parental perceived threat or loss – the feeling that ASD diagnosis threatens the family functioning (Turnage, 2022). Protective factors appear to be the ability of the child to communicate and take care of its basic needs, family income and higher education of parents, as well as social support to the family (Turnage, 2022). Other data suggest that increased parental involvement in the interventions (such as parent training, homework routines etc.) might also be a way to promote the caregivers' quality of life (Musetti, 2021).

Persons with ASD - the significance of adequate support

Taking care of a person with ASD represents an immense challenge – regarding basic functional impairment, behavioral symptoms and comorbidities.

Families of children and young people with autism spectrum disorders need to be continuously and comprehensively supported in order to provide and maintain an optimal level of care.

ASD is a lifelong condition and people with ASD have various needs (educational, medical, social, etc.) related to this condition throughout their lives. In order to enable people with ASD to live as independently as possible, it is necessary for the support services to provide diverse approaches and strategies based on evidence and good practices. Multisectoral cooperation is necessary, where each of the systems should allow for planning, designing and providing support with good cooperation with the other systems. Right now, parents sometimes happen to “wander around” within the support system. It is possible to consult several doctors

and medical workers, and encounter different strategic approaches to ASD.

Lack of coordination among the systems is common, as are different levels of mutual support. Achieving coordinated cooperation among the systems would provide comprehensive support to children with ASD and their families (Veljković, 2018).

In Serbia, a system of services is included in care for persons with ASD and their families; healthcare, education (inclusion, additional educational support) as well as social care and protection. The legal framework of the Republic of Serbia guarantees a universal availability of health services for all children.

Although the Republic of Serbia has, in large, reformed the laws and policies for the rights of children with disability, and different levels of support exist, persons with ASD and their families are often faced with issues in education, stigmatization, and financial difficulties (Pejovic-Milovancevic, 2018). Services are usually provided only in larger cities, implemented through project activities, therefore not permanent. Support such as daily care is significant, but not sufficient. There is a lack of services focused directly on the families, and it is recognized by the parents/caregivers (Pejovic-Milovancevic, 2018).

In a recent study done on a sample of children with ASD (mean age 10.5) in Serbia, it was shown that the most important challenges related to care were child's communication difficulties, social interaction difficulties, and problems with daily living skills. The overall satisfaction of parents with ASD was related to having additional assistance for the child with ASD, and inversely related to difficulties with accessing services for the child in the past 12 months (Pejovic-Milovancevic, 2018). In a recent scoping review regarding parental experiences in raising children with ASD in Eastern Europe, it was shown that, consistent with studies conducted in Western countries, parents of children with ASD expressed more personal and family challenges and greater maladaptation compared to parents of TD children. Moreover, families reported lower satisfaction with quality of life and more health problems (Čolić, 2019).

AIM

The main aim of this study is mapping available support services for young people with ASD and their families and assessing their greatest needs. Also, the study is aimed towards examining the perception and attitudes of the parents/caregivers towards the existing support system.

METHOD

Questionnaire

For this survey, we have used an adapted version of The Caregiver Needs Survey (SEAN) (Daniels, 2017). The survey is intended for parents or primary caregivers of children with a diagnosis of ASD. The survey consists of four parts: demographic characteristics, child characteristics, experiences with services and parent/caregiver perceptions on main issues and priorities regarding care for children with ASD. The part covering demographic characteristics included questions on the characteristics of family, such as educational level of parents. The part covering characteristics of the child included questions on the diagnosis, sex, age, and details on the condition of the child and the diagnostic process – initial concerns, age at diagnosis, the professional who initially formulated the diagnosis of ASD and the distance from the place of residence to the health institution where the diagnosis was established.

The part regarding experiences with services inquired about past and current involvement in different treatments and engagements with different professionals, as well as the experiences within the educational system, including additional assistance services. The part regarding experiences with services was altered, specifically by adding information on daily-care facilities, since those become more important as the child with ASD finishes education. The part covering parent/caregiver perceptions provided an opportunity to discuss the delays or difficulties in accessing services due to different reasons, effects on the family functioning and the quality of life. This section also involved questions about the most important perceived challenges and priorities in providing support for families with children with ASD.

Study participants and procedure

The study included parents/caregivers of adolescents and young adults with ASD – from 15 to 30 years of age. The participants were recruited from the database of the Institute of Mental Health. They were contacted via telephone, or asked to participate during a regular check-up. Part of the surveys was done in person, while a part was done via phone, or in an e-format and sent back via e-mail. The average completion time is 30 minutes.

The study was approved by the Ethics Committee of the Institute of Mental Health in Belgrade. Prior to participation, all of the participants signed an informed consent. The study was conducted between October and December 2022.

Sample

The sample included 85 parents/caregivers; 69 mothers, 15 fathers and 1 sister of a patient with ASD. The average age of the child in the moment of parental interview was 19.7 years (SD 4.2). 40.5% of parents/caregivers had a university degree. Of the whole sample, 63.7% of the questionnaire was done personally (23.5% in the presence of the examiner and 41.2% independently), 14.1% was done via phone, while 21.2% was sent back to the examiners via email.

Statistical analysis

The descriptive data were analyzed through percentages, frequencies, means and standard deviations. As a first step in further analysis, we conducted bivariate analyses with all of the explored variables, using Pearson's correlation. Additionally, we performed a multiple linear regression analysis, a model using satisfaction with support as outcome and significant variables (bivariate correlates) as predictors.

RESULTS

In this study we have approached parents/caregivers of 154 patients with ASD. From the caregivers included in the survey, the majority of them were mothers (69 of 85).

This finding is similar to that obtained in a previous study done in our country (Pejovic Milovancevic et al, 2018). Mothers are the ones that more frequently care for children's needs, and they are commonly stay-at-home parents, while fathers are more frequently playing a role of financial providers (Dokmanovic 2016).

We obtained answers form 85 parents, as 69 refused to participate.

From each family we only ask one family member to answer the questions. The most common reason for refusing participation in the survey was their overwhelmed schedule: most of them explained that they either work or do the house work in the morning, while their child is in school or daycare center, and explained that it was very hard for them to find time to fulfill the questionnaire in the afternoon, when they needed to focus all of their attention to their child (the most common reason was disruptive behavior). Few parents refused to parti-

cipate with no given reason, and very few of them were suspicious about the purpose of the study, even though they were shown informed consent, and explained all the details about the study. Yet, the majority of them expressed hope that this study will help to inform policy makers and stakeholders, they were grateful to have the opportunity to be heard and were willing to focus on the most important issues for them.

In our survey, the majority questionnaires were answered by the mothers (81.2%).

All of the other participants were fathers of the child, except for one, which was answered by a sister of a patient. A large proportion of parents (97.6%) had an education of secondary school or higher, which is in concordance to previous studies, showing that parents of children with autism have higher education than the general population (Zuckerman, 2017). Most of the people interviewed live in urban areas (96.4%). This finding might be due to the fact that this is a convenient sample from the Institute of Mental Health in Belgrade, which covers mostly Belgrade and surrounding areas. These data are presented in **Table 1**.

Table 1. The sociodemographic data of parents/caregivers.

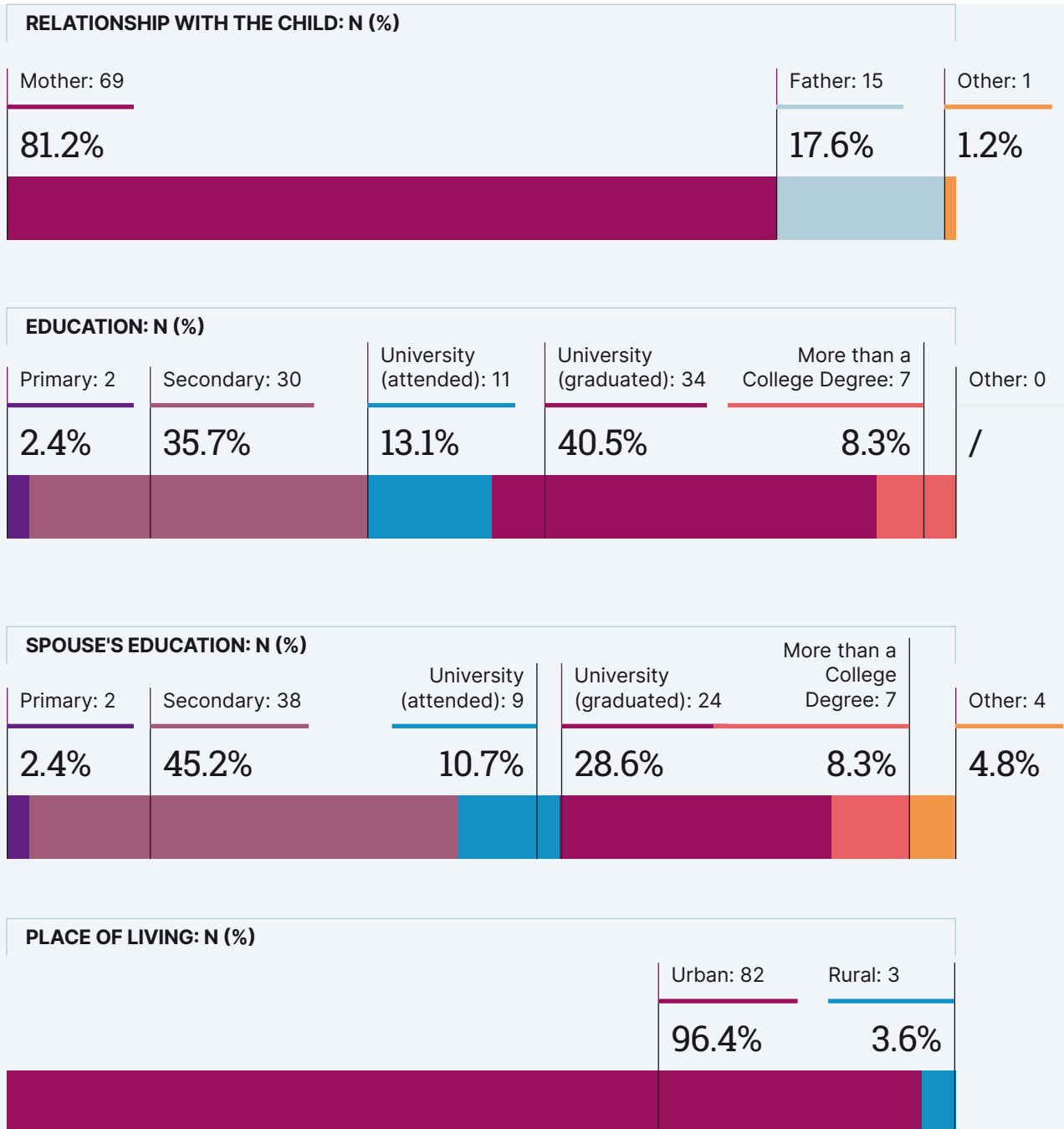
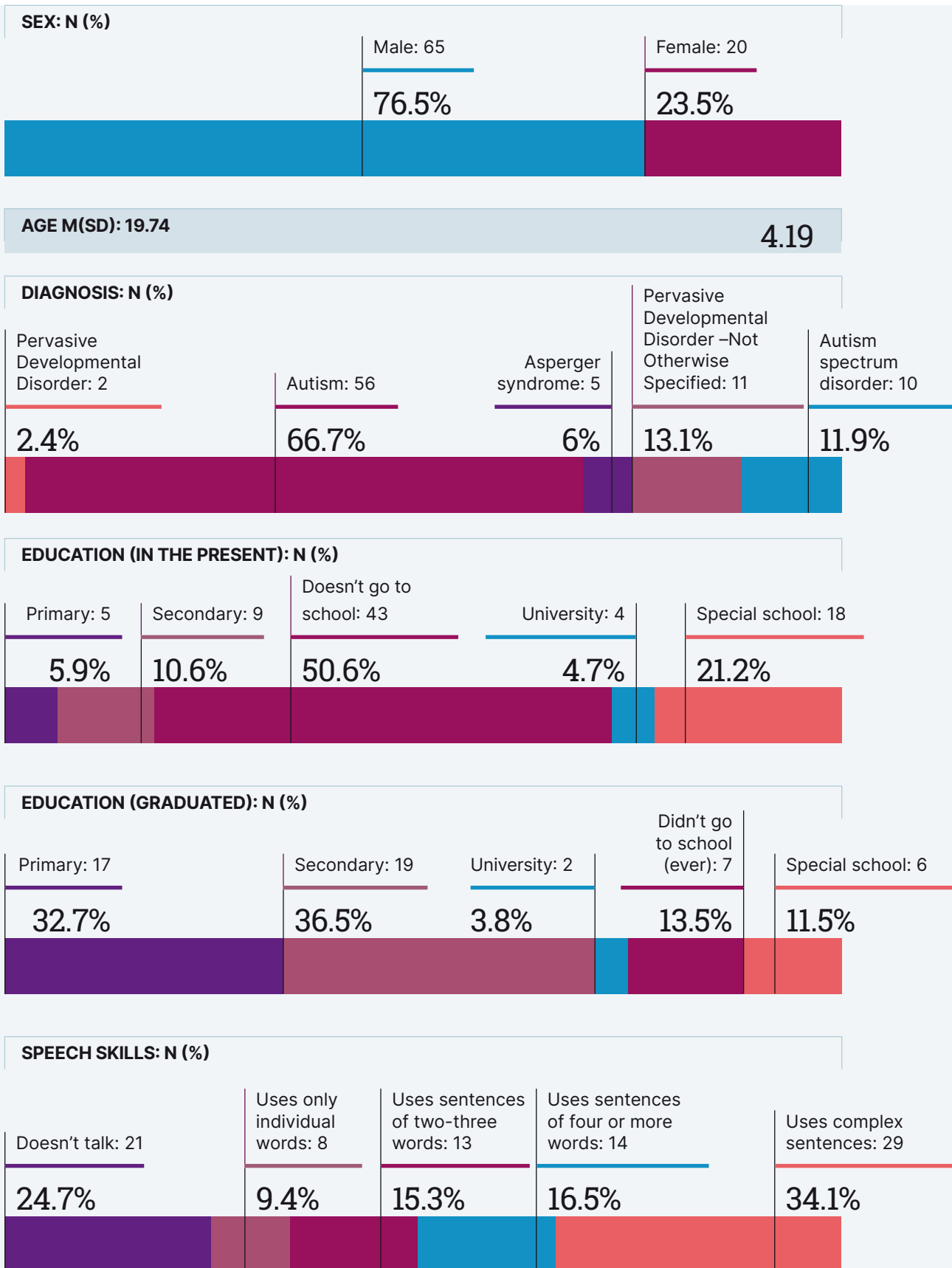


Table 2. The sociodemographic data and speech skills of adolescents and young adults with ASD.





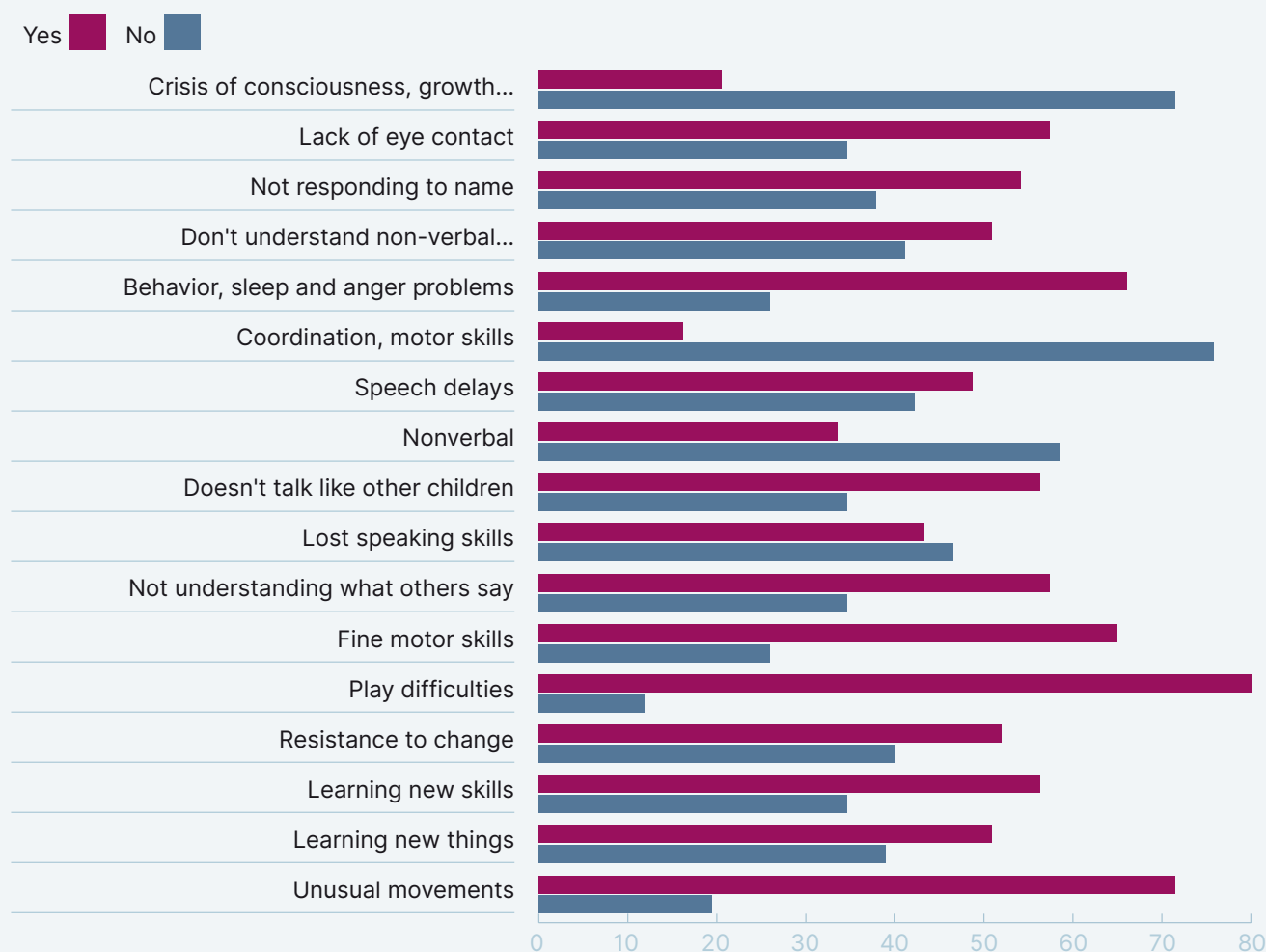
More than two thirds of adolescents and young adults with ASD in our sample were male (76.5%), showing similar male to female ratio found in other epidemiological studies (about 4.2) (Zeidan, 2022). According to their age, more than a half of young people with ASD do not go to school (54.4%) – others included in this sample mostly finished primary and secondary school, about two-thirds. In the context of speech skills, most of them either do not speak or use complex sentences.

These data are presented in **Table 2**.

Graph 1 presents the first symptoms of parental concerns regarding their child's development. Top three first concerns of parents were child's behavior, sleep and anger problems, unusual movements, and difficulties with engaging in play activities.

These results are partially different from those done in Serbia in 2018, on a sample of children (mean age 10.5), where besides unusual gestures and movements, main problems were problems of interacting with others and not understanding what parents or other adults said to him/her (Veljković, 2018). The explanation might be recall bias – parents of adolescents and young adults might be focused on problems that have been present in the recent past, or that require the most attention or pharmacological interventions, such as behavioral and anger issues.

⬇ **Graph 1.** The first symptoms and concerns.



The average age of first concerns in our survey was 23.6 months (SD20.06), while the mean age for diagnosis was 62.48 months (SD41.73).

As it is shown, there is a great time lag between noticing the first symptoms and diagnosis. These results are in accordance with previous studies.

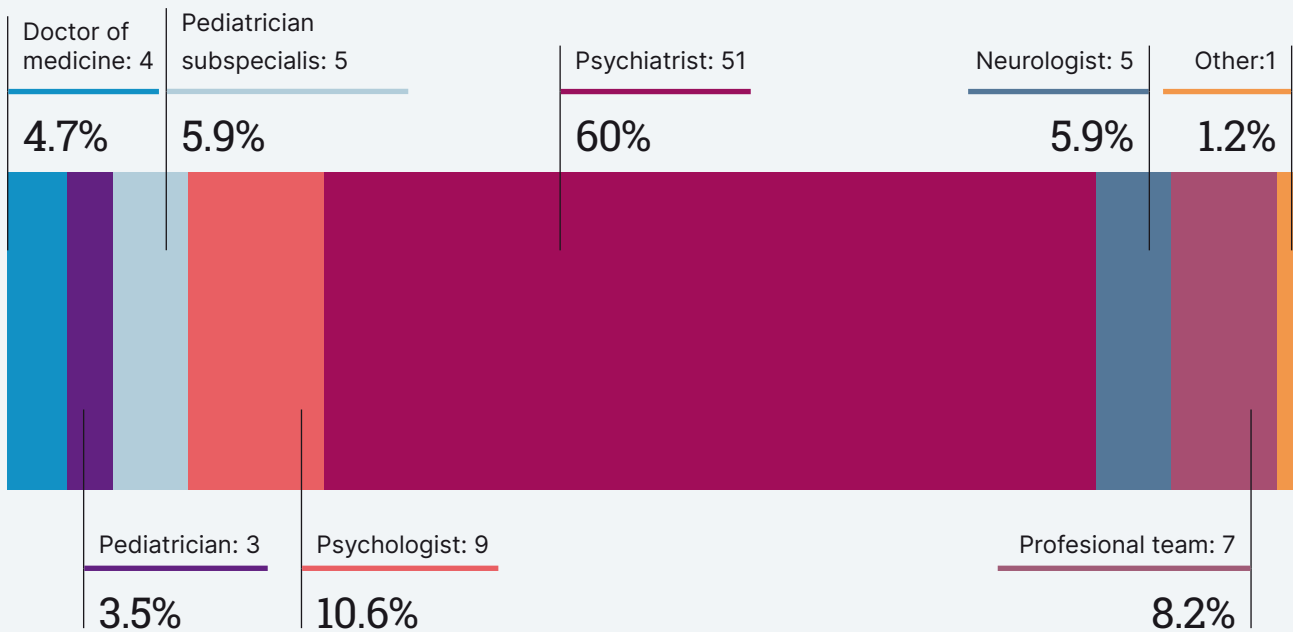
A survey of over 1000 parents in the United Kingdom has shown delay of around 3.5 years from the moment when parents and children first approached a health professional to the diagnosis of an autism spectrum disorder (Crane, 2016).

In Serbia, there is still need to develop systematic screening for developmental disorders; currently, besides regular checkup at pediatricians, there is no other re-

gular developmental assessment of children. Detection of symptoms depends on parents, meaning when they first notice the problem, as well as when they express the problem to the doctor.

In more than half of the cases (60%), the diagnosis was made by a child psychiatrist. In the section other, in one case, the diagnosis was made by a special educator (dialectologist, speech therapist or similar). These results are shown in graph 2. The increase in the percentage of diagnoses made by child psychiatrists could be influenced by overcoming barriers such as increased knowledge and awareness of ASD and knowing where to go for help. Potential barriers that lead to disparities in diagnosis can be found in the literature, such as stress of the diagnostic process, parent knowledge about ASD and understanding of the medical system (Zuckerman KE, 2017).

⬇ **Graph 2.** Who made diagnosis of ASD?



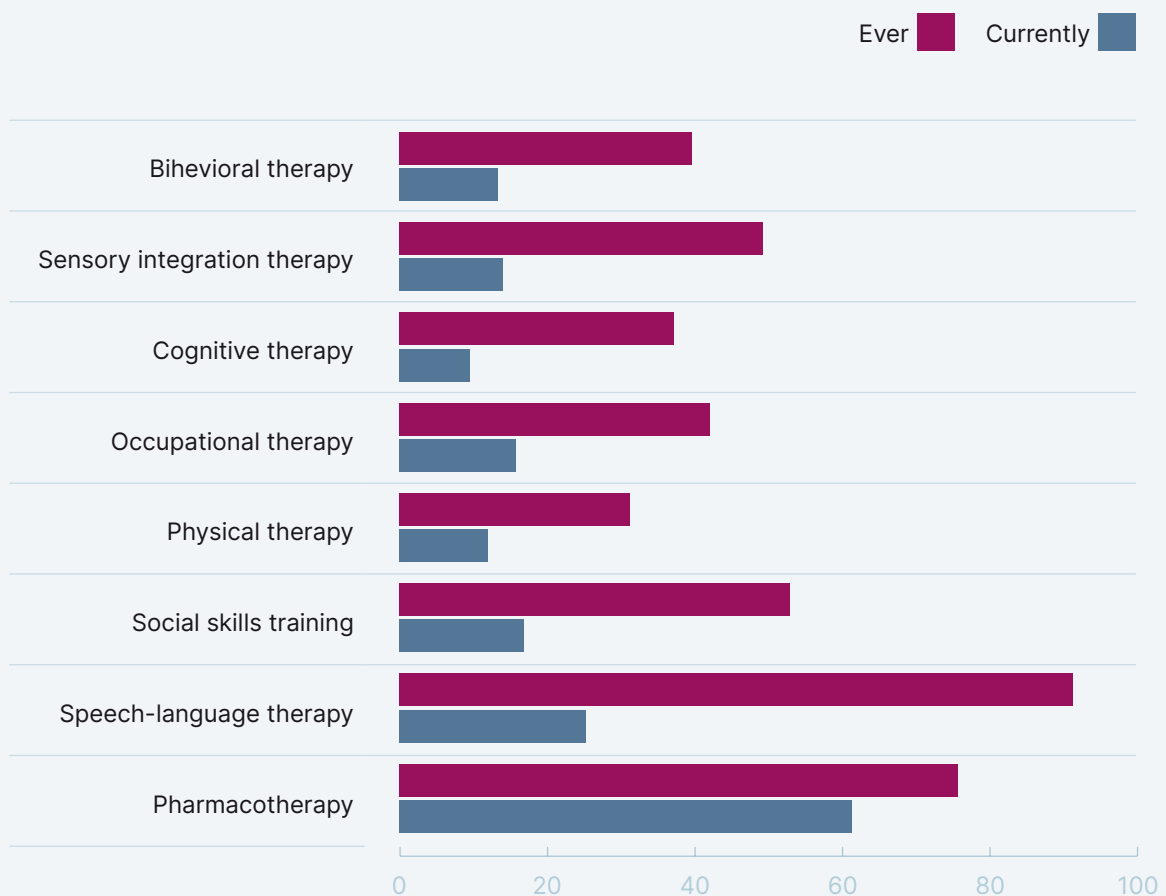
Experience with services

One part of the questionnaire was dedicated to collecting data about the availability of services and treatments, and parents' experiences related to those services.

Graph 3 represents the use of different types of treatments. Most of the possible treatments were used in the past, but not currently. Most of the treatments listed are being used in earlier phases of development, therefore they are used to the lesser percent in the present. Yet, the greatest number of children is using pharmacotherapy at the present moment.

When it comes to services' availability, in our sample, the services are mostly located within 25 kilometers (71.1%), in 7.2% of cases they are located between 25 and 50 kilometers and between 50 and 100 kilometers, respectively. In 10.8% of cases, the place of living was more than 100 kilometers away, while in 2.4% the services are located in another state.

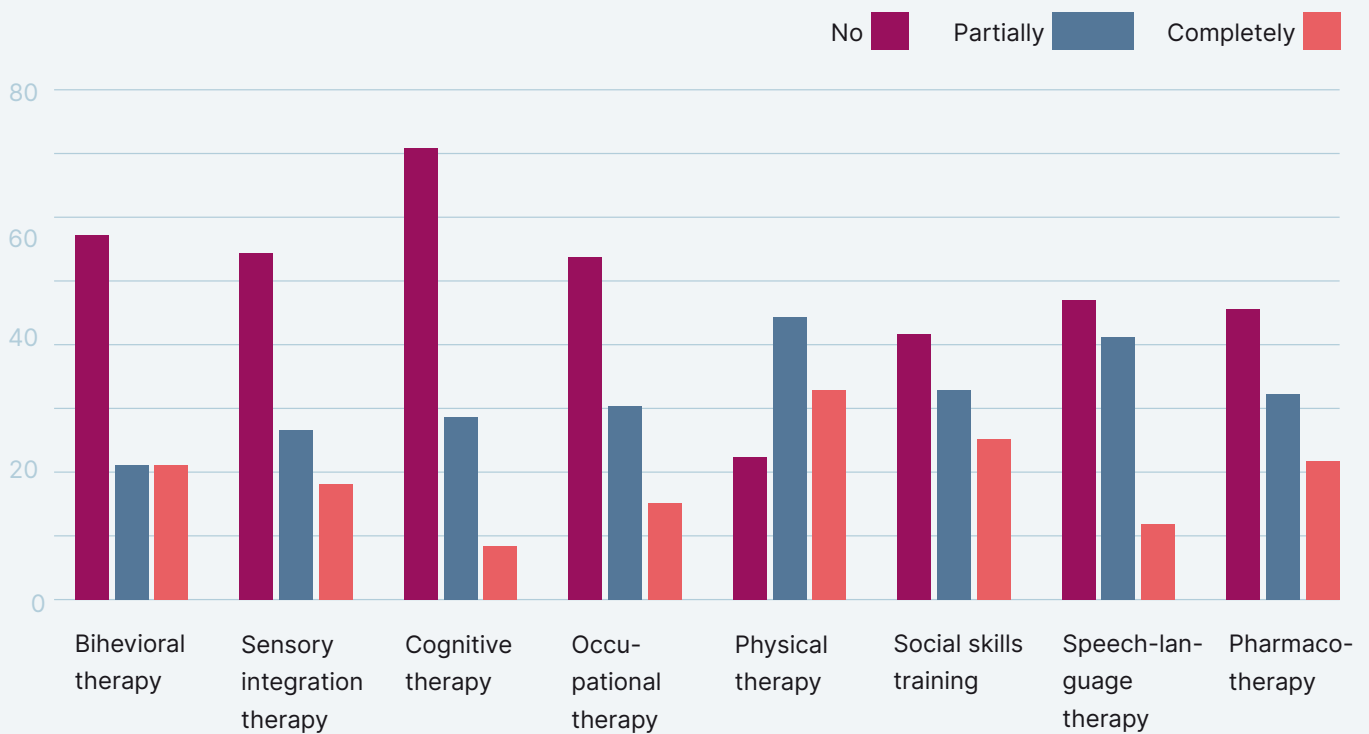
⬇ **Graph 3.** Type of treatment used ever/currently (%).



Graph 4 shows the funding of the above mentioned treatments. We asked whether parents pay completely by themselves for the treatments, or if some of the treatments are covered by the public funds (health insurance). The type of the treatment for which most of the

parents paid by themselves was shown to be physical therapy. Also, almost half of the parents said that speech-language therapy is partially covered by funds, and one third of them are paying for the social skills training, occupational and cognitive therapy.

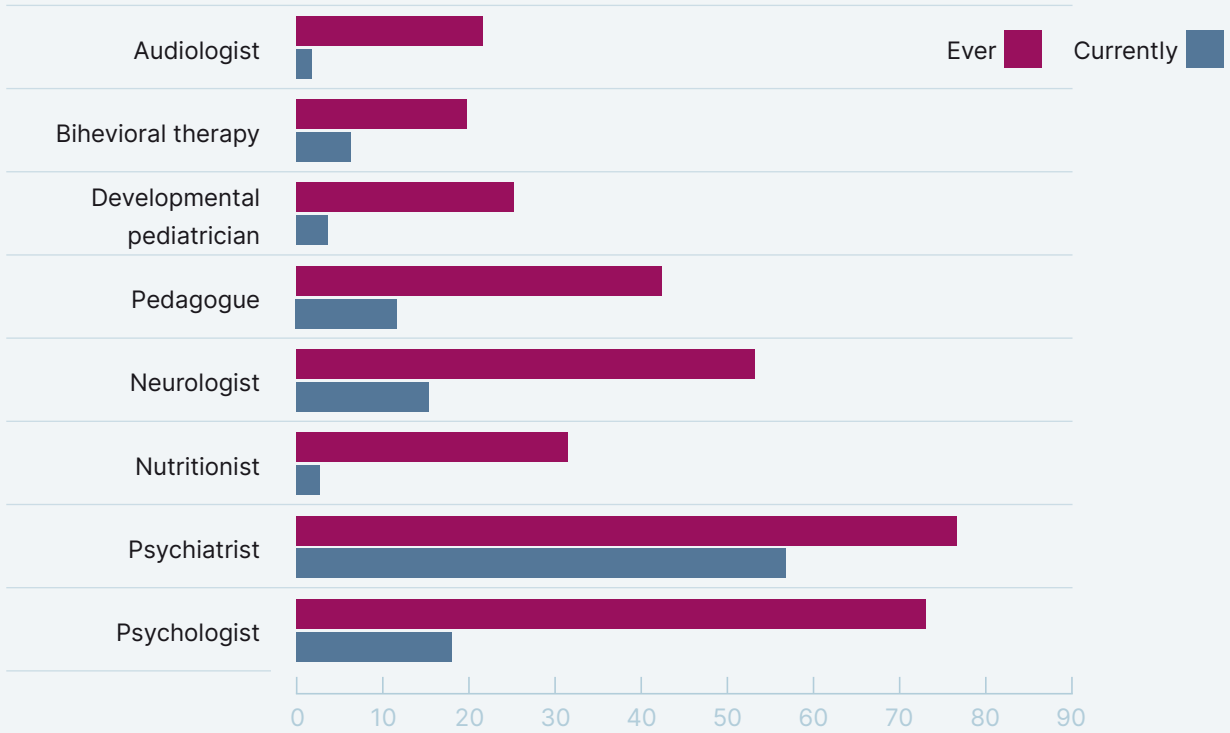
⬇ **Graph 4.** Paying for the treatment (%): No means that the treatment is covered by the state funds, completely - that the parents are paying completely by themselves.



Graph 5 represents the use of different types of professional treatments. Data show that most of the professional services were used in the past, but not currently, except for the psychiatrist's treatment, as out of 85 young persons with ASD, over 50 are still treated by a psychiatrist. It might be said that most of the mentioned professional services are diagnostic by nature. For example, the purpose of an audiologist ex-

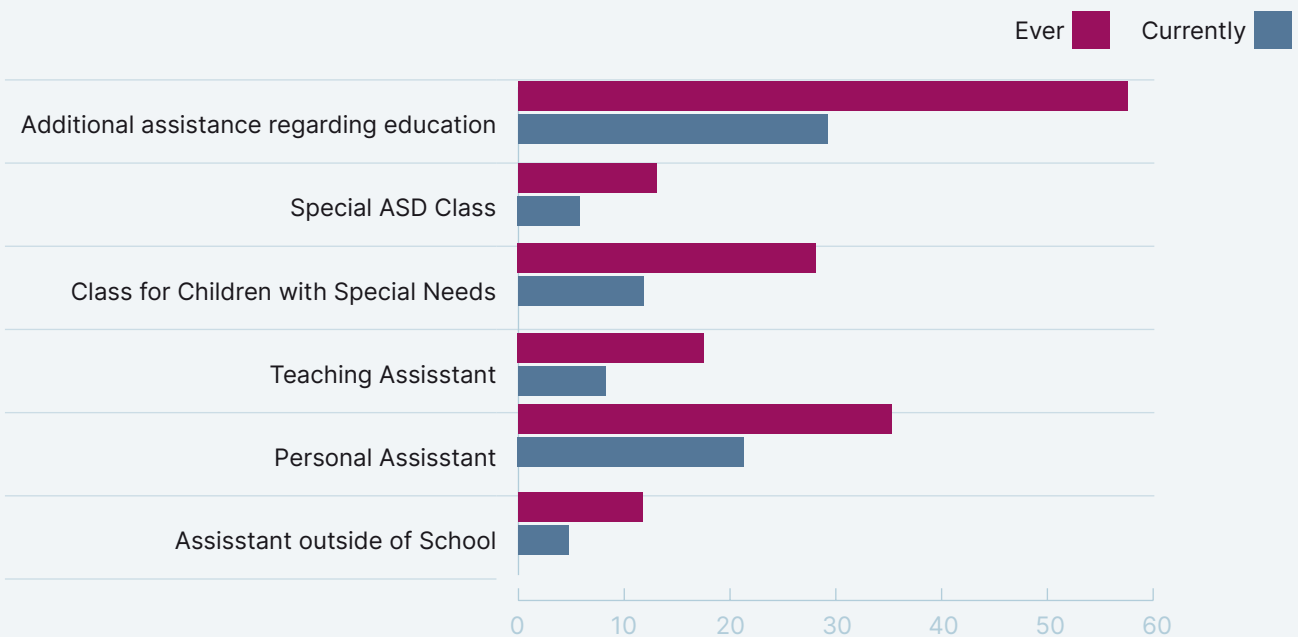
amination is usually for differential diagnosis at the beginning of the diagnostic process. On the other hand, one of the possible reasons for the lower rate of using services in persons with ASD with age could be lack of information about available services, or lack of tailored treatments for adolescents and young adults with ASD (Hodgetts, 2014).

Graph 5. Treated by a professional ever/currently (%).



Graph 6 indicates the utility of additional assistance regarding education. Our data indicates that the majority of children used additional assistance in the past, while less than 30 percent of children still use those services.

Graph 6. Additional help.

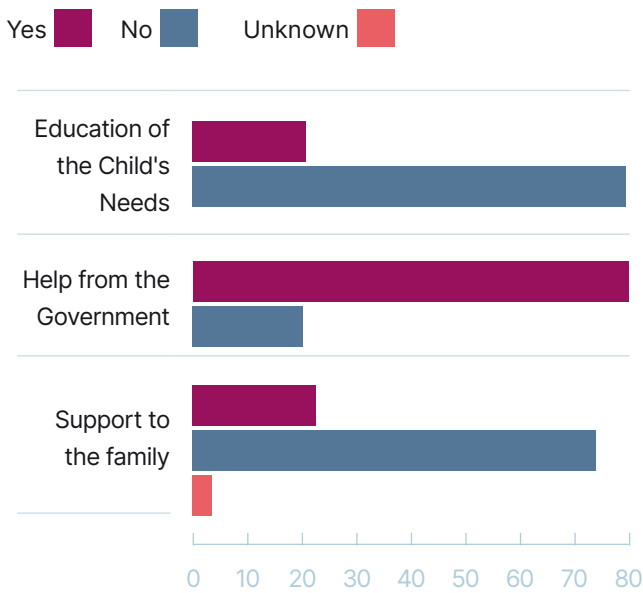


As indicated in **Graph 7**, the majority of parents reported receiving some kind of help from the Government. Parents primarily mentioned financial aid as an important asset. The financial support for families of youth with ASD is mostly through social services aid - financial compensation for help and care by another person. Only a minority of parents received education on their children's needs and parenting challenges, pointing out daily care, doctors from primary medical care and psychiatrists, as well as parental organizations as impor-

tant sources of support. Support to the family mostly includes information and help from the independent parental organizations. In another relevant research, parents reported the support of their spouse, another child, grandparents and doctors to be of the greatest importance for them (Nooraini, 2018).

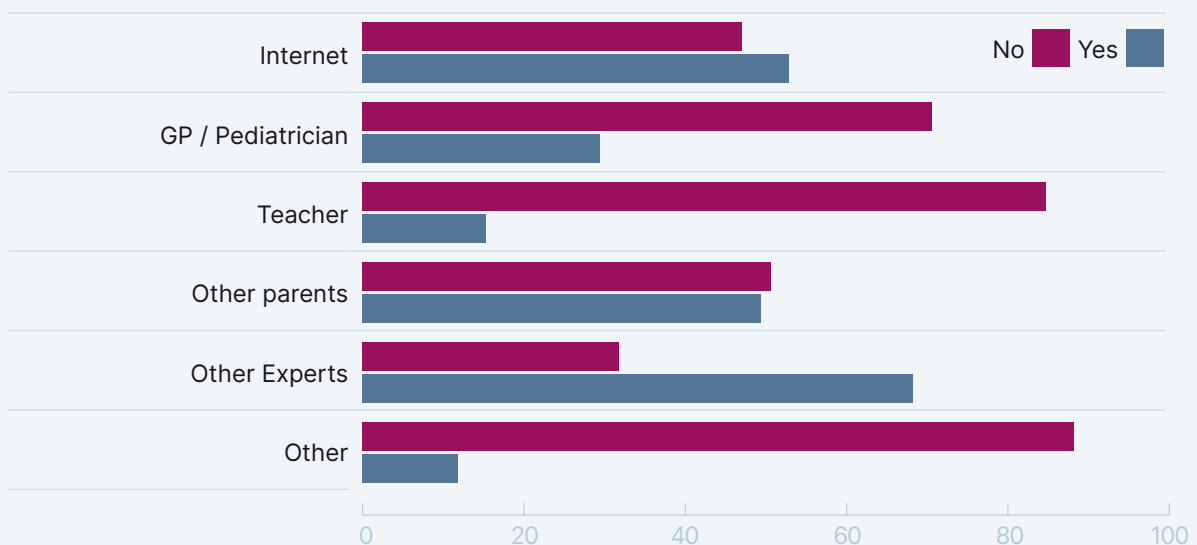
Although financial support is of undoubted importance, we can assume that families of children with ASD could benefit from education on challenges and how to overcome them, and from the additional family support as well.

Graph 7. Additional assistance to the parents (%).



When it comes to information regarding their child's treatment, the majority of parents receive the information from experts involved in their child's care. About half of the parents turn to the Internet and to other parents looking for information. GP/pediatricians and teachers are only recognized as a source of information by a minority of parents. Among other sources, the parents mentioned defectologists, as well as professional literature and magazines. These results are presented in Graph 8. Literature findings support the importance of information availability, as in Hodgetts' paper, where they found out that most frequently unmet service needs were information on services, family support, and respite care. (Hodgetts, 2014).

Graph 8. Sources of information for the parents/caregivers (%).



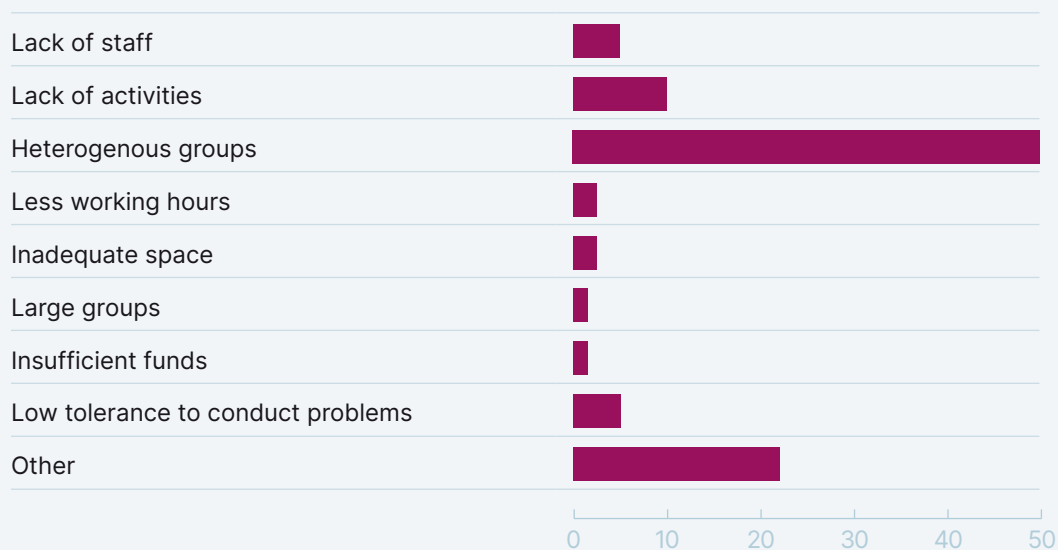
In our sample, the majority of parents (68%) reports that their child is not attending a daily care center (DCC). Most of the parents whose child is attending DCC, highlight heterogeneous groups to be one of the greatest problems, since it potentially lowers the capacity of the staff to meet the needs of the children, as well to get along with their conduct problems, which was also reported as an issue. Some parents reported the issue of the lack of activities, lack of staff and insufficient funds. Also, other issues are short working hours, inadequate space and large number of children in the DCC group.

When it comes to parents whose child does not attend a DCC, they highlighted unavailability as a major issue and reason for not attending: either due to the long distance between DCC and their homes, or long waiting

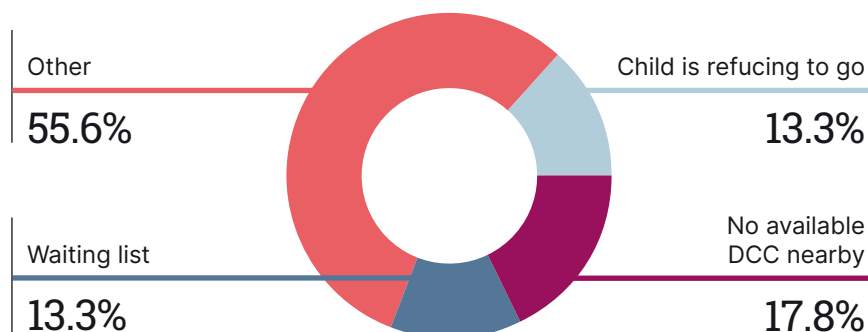
lists. According to data that are available in the report of the Social Inclusion and Poverty Reduction Unit Government of the Republic of Serbia, DCC for children (and youth) with developmental and other disabilities was the second most prevalent social care service within the mandate of local governments. In this report from 2016, it was stated that DCCs were available in 68 local governments in Serbia (Matkovic and Stranjakovic, 2016). Under the Law on Social Protection (Article 41), the beneficiaries of DCCs are minors (children) and adults (youth) up to the age of 26 with developmental disabilities - some of the parents in our research reported age limitation as one of the reasons for not attending it. According to the abovementioned report, in 2016 the clients were predominantly males from urban areas (Matkovic and Stranjakovic, 2016).

The problems in DCC and reasons for not attending are shown in **Graph 9** and **10**, respectively.

⬇ **Graph 9.** Problems related to DCC (%).



⬇ **Graph 10.** Reasons for not attending DCC (%).



Parent/caregiver perceptions

A series of questions covered different kinds of problems faced by the parents and caregivers while providing care to their child with ASD in the past year. The answers are shown in **Graph 11**.

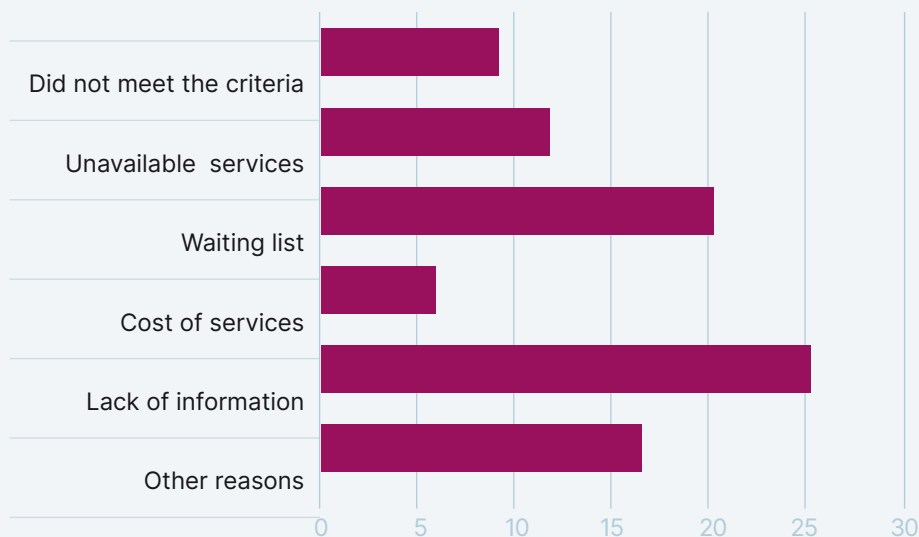
The majority of parents pointed out lack of information and waiting lists as common reasons for unavailability of services.

The parents also mentioned the difficulties in scheduling appointments with professionals, obstacles specific to particular age of the child, difficulties regarding personal assistants and pandemics as factors influencing the lack of services. Those results are partially in accordance with the data obtained in a survey performed on a sample of 758 caregivers of persons with ASD from four countries in Southeast Europe – Albania,

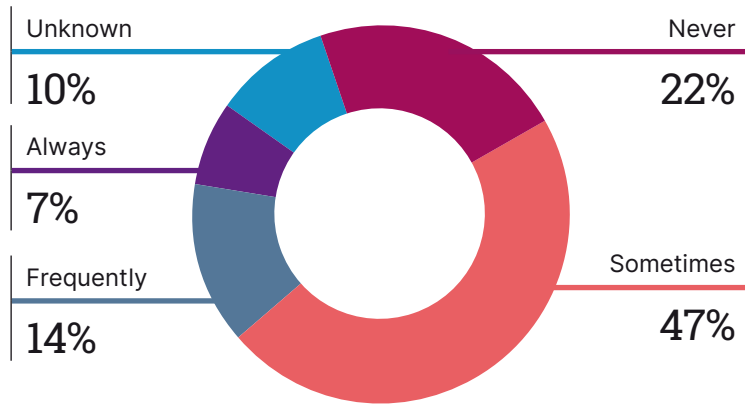
Bulgaria, Croatia and Turkey, where 31% of participants reported lack of information as a reason for the delay in accessing services; while 29% pointed out long waiting lists as the reason for unavailability of services. In this regional study, 31% of the participants reported delays in accessing services due to failure to meet particular criteria; 35% reported delays in accessing services due to their unavailability, while 31% mentioned the cost of services as the reason for the delayed access (Daniels et al, 2017).

In a study performed at two time points in The Republic of North Macedonia (in 2015 and 2020) the parents reported delays in accessing services due to high cost (33% in 2015 compared to 46% in 2020), lack of information (41% in 2015 compared to 49% in 2020), unavailability of services (65% vs 73%) and long waiting lists (57% vs 56%) (Zorcec and Pop-Jordanova, 2020). In a survey with parents of adolescents and adults with autism performed in Poland in 2014, the most frequently mentioned barriers in accessing services were the unavailability of the desired services and the high cost of services (Platos and Pisula, 2019).

↓ **Graph 11.** Unavailability of services in the past year.



⬇️ **Graph 12.** Parental frustration in the previous year (%).



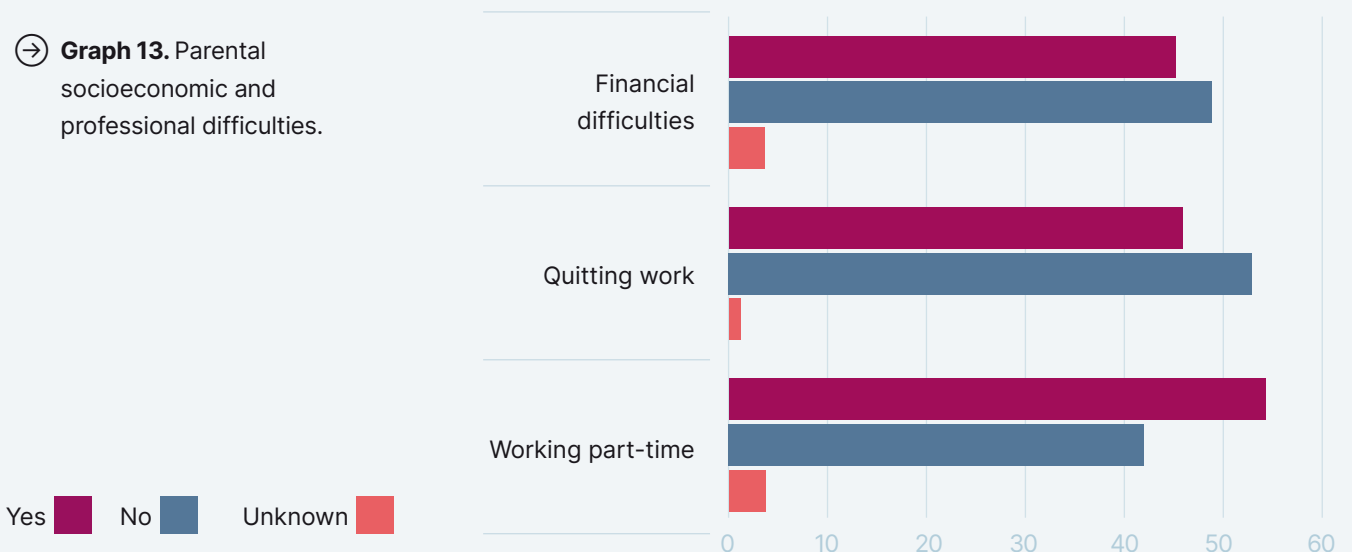
When asked about feeling frustrated in the past year, the majority of the parents reported that it happened sometimes. The results are shown in **Graph 12**. In the previous study performed in 2016 and 2017, which involved 231 parents of patients with ASD of the Institute of Mental Health in Belgrade, Serbia, about one third of the interviewed parents reported being frustrated in efforts to obtain services for their child in the past 12 months (Pejovic-Milovancevic et al, 2018). In the survey performed in the four countries of Southeast Europe, 73% of participants reported at least some level of frustration in the past year (Daniels et al, 2017).

These data might be indicative that social support of caregivers of persons with autism can partially media-

te the relationship between coping – positive (actively seeking help and cognitive reconstruction) or negative (avoidance and disengagement) and family quality of life (Wang et al, 2022).

Graph 13 indicates parent-reported socioeconomic and professional difficulties related to their child having autism spectrum disorder. The majority of parents (52.9%) reported that they had to quit work and almost half of them (48.8%) pointed out that they have met financial difficulties, while 42% of parents reported working part-time in order to meet increased demands of parenting. In the abovementioned study, 70% of parents reported having financial difficulties due to the child's diagnosis (Pejovic-Milovancevic et al, 2018).

➔ **Graph 13.** Parental socioeconomic and professional difficulties.



The results obtained in a study performed in The Republic of North Macedonia reported negative impact on family finances as the most common complaint regarding socio economic difficulties (75% in the survey performed in 2015 and 76% in the survey performed in 2020) (Zorcec and Pop-Jordanova, 2020).

Data from the regional survey indicated that two thirds of caregivers reported financial difficulties of the family caused by having a child with ASD, and almost half of the parents reported the need to quit working or work part-time (Daniels et al, 2017).

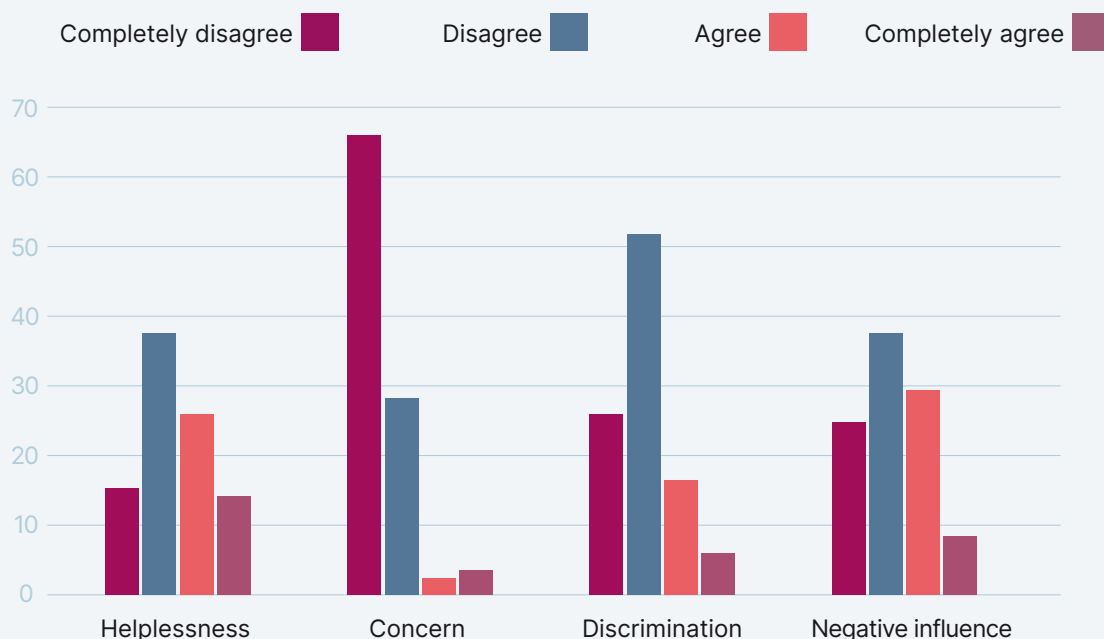
Parents/caregivers were also asked to state whether certain issues regarding their child’s diagnosis of ASD have had a negative influence on them: feeling helpless, concerns about other people finding out about the diagnosis, feeling discriminated against due to their child’s diagnosis and being negatively influenced by the ASD diagnosis of their child. The majority of parents denied feeling concerned that other people would find out about their child’s diagnosis (94.1% in total), which is in accordance with the previous study where 95% of parents denied this concern (Pejovic-

ic-Milovancevic et al, 2018). In the study performed in the region of Southeast Europe, 71% of the participants denied feeling worried on this subject (Daniels et al, 2017), while in a study performed in The Republic of North Macedonia only about 35% of participants denied feeling concerned about other people knowing about their child’s diagnosis (Zorcec and Pop-Jordanova, 2020).

In our research 77.7% of parents also denied experiencing discrimination, which is higher than the previously reported results in our population (69.6%) (Pejovic-Milovancevic et al, 2018) and in a large regional sample (59%) (Daniels et al, 2017). On the other hand, 66-76% of the sample collected in The Republic of North Macedonia reported experiencing discrimination (Zorcec and Pop-Jordanova, 2020).

More than half of the parents do not feel that their child’s diagnosis influences them in negative manner (62.3% in total), which is lower compared to previously reported results in our population (71.7%) (Pejovic-Milovancevic et al, 2018), similar to results obtained in the Republic of North Macedonia (63-72%) (Zorcec and Pop-Jordanova, 2020) and somewhat higher compared to data obtained in the countries in the region (58%) (Daniels et al, 2017).

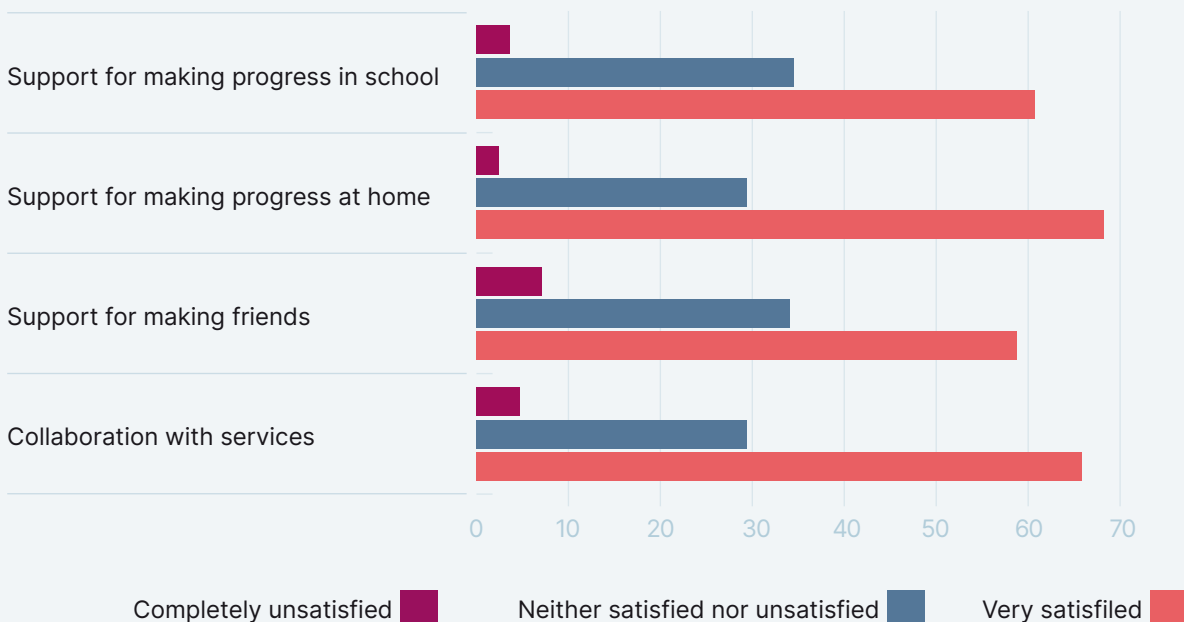
Graph 14. Negative experiences related to ASD diagnosis



Over 95% of parents/caregivers stated that good collaboration with services involved in care for children with ASD, as well as support at home and at school is important or very important. This was also stated for the importance of support in making friends, in 92.9%. Those results are in accordance with previously reported data indicating that over 90% of parents in Serbia, as well as the majority of the participants in Albania, Croatia, Bulgaria and Turkey consider those components of support important (Pejovic-Milovancevic et al, 2018; Daniels et al, 2017). **Graph 15** shows satisfaction with the abovementioned support for children with ASD.

When it comes to satisfaction with support in four different contexts – school, home, making friends and collaboration with services, we created a scale ranging from 4 to 12. The score of 4 means that the parent/caregiver is completely unsatisfied with the support, while the score of 12 stands for being very satisfied with all of the four fields. The mean score was 8.2 (SD 2.1). In the previous study, when asked about their satisfaction with support, about half of the parents were neutral, with a higher number of parents who felt very satisfied compared to those who felt very dissatisfied (Pejovic-Milovancevic et al, 2018).

Ⓣ **Graph 15.** Satisfaction with support for children with ASD.



In a large regional sample, 25% of the participants reported being very dissatisfied with support for making progress at school, 21% reported dissatisfaction with services encouraging progress at home and 29% reported dissatisfaction with support for making friends, while only 5% of participants were dissatisfied with collaboration with services (Daniels et al, 2017). On the sample of caregivers in The Republic of North Macedonia, the majority of the families reported lack of support to make friends among peers (37-54%) and support to improve at home (38% -51%) (Zorcec and Pop-Jordanova, 2020).

We performed bivariate analyses (Pearson's correlation), having total satisfaction score (TSS) as the outcome and all of the questioned variables as potential predictors. During the analyses, we found that the TSS was significantly associated with several variables. Higher TSS meaning greater overall satisfaction correlated with currently being treated by a psychologist ($R_{pbis}=0.232$, $p=0.037$), with currently using special ASD classroom ($R_{pbis}=0.244$, $p=0.028$), with having general practitioner medical doctor of pediatrician as the source of information ($R_{pbis}=0.297$, $p=0.007$), as well as using the services of a nutritionist (ever) ($R_{pbis}=0.225$, $p=0.043$). In the previous study, higher

satisfaction correlated with having an in-school tutor and training or assistance in managing child's needs or implementing; furthermore, the variable of having primary care doctor or pediatrician as a source of information on autism ($t=3.830$, $p=0.000$) as well correlated with higher reported satisfaction (Pejovic-Milovancevic et al, 2018).

On the other hand, lower TSS score, meaning lower overall satisfaction with the services was associated with the use of a personal assistant (ever) ($R_{pbis}=-0.259$, $p=0.019$), being frustrated with the services in the past year ($R_{pbis}=-0.423$, $p=0.000$), and feeling helpless regarding having a child with ASD ($R_{pbis}=-0.292$, $p=0.011$). While in the previous study frustration with services in the past year and feeling helpless correlated with lower overall satisfaction with the services as well, several other variables were also found to relate to dissatisfaction, such as the presence of particular initial concerns (not responding when called, difficulties

in nonverbal communication, difficulties understanding verbal information, problems of interacting with others or playing alone and difficulties in learning new skills), parental education beyond secondary school, financial problems due to autism and experiencing discrimination (Pejovic-Milovancevic et al, 2018).

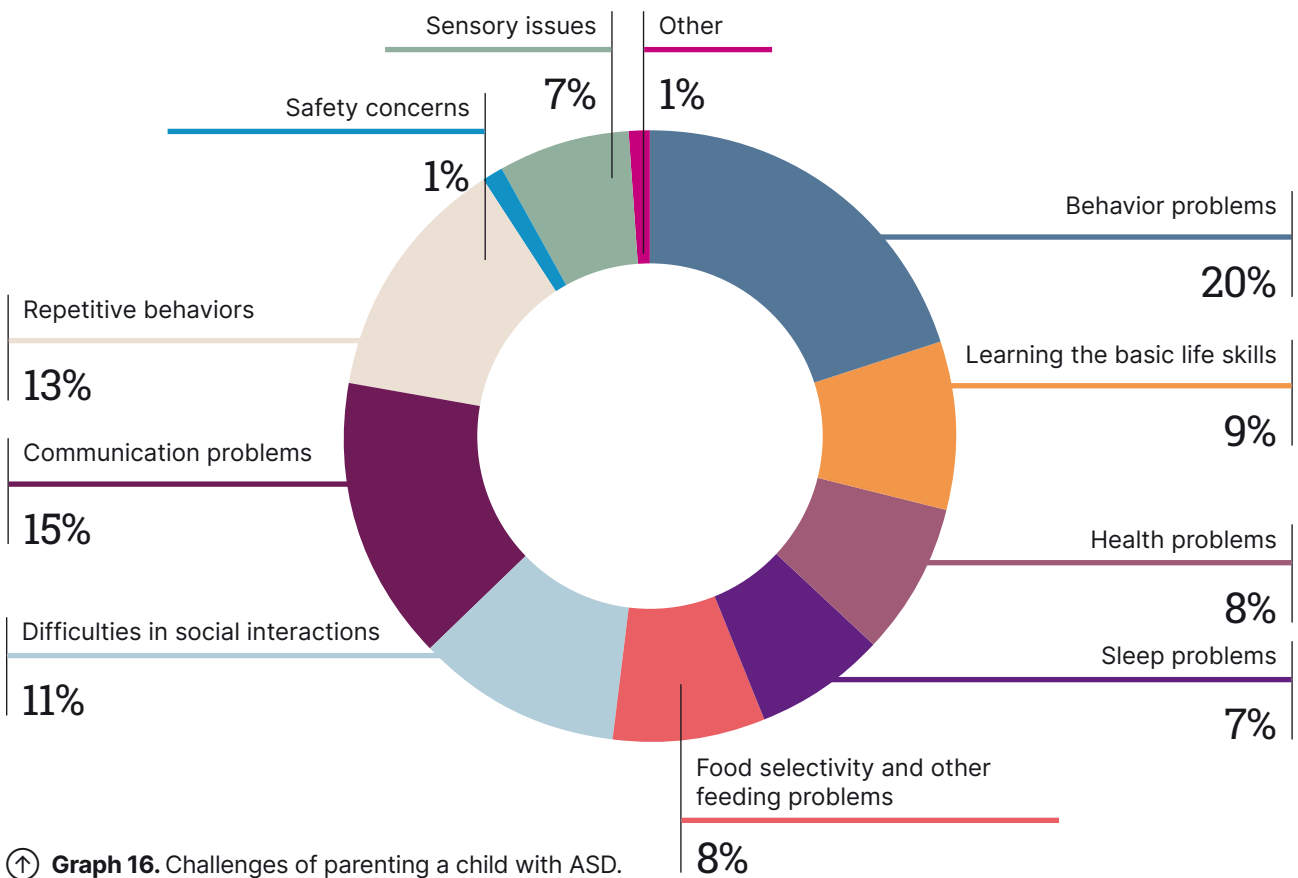
After controlling for relative effects, the significant predictors of lower overall satisfaction with support was feeling helplessness regarding having a child with autism (Table 3), which differs from the model obtained in the previous research, highlighting parental higher education, initial concerns regarding problems of interacting with others or playing alone and parent being frustrated over access to services in the previous year as significant predictors of lower overall satisfaction with support (Pejovic-Milovancevic et al, 2018).

Table 3. Multiple linear regression model of total score of satisfaction (TSS).

Predictors (variables with significant bivariate associations with the outcome)	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
Treated by a psychologist (currently)	.679	.572	.125	1.188	.239
Using the special classroom for ASD (currently)	2.051	1.136	.202	1.806	.075
GP or pediatrician as the source of information	.610	.489	.133	1.247	.217
Feeling frustrated with the services in the past year	-.406	.219	-.208	-1.859	.067
Treated by a nutritionist (ever)	.813	.448	.191	1.814	.074
Personal assistant (ever)	-.460	.451	-.111	-1.020	.311
Feeling helpless	-1.098	.457	-.273	-2.404	.019

Graph 16 presents various challenges faced by parents of children with ASD. As it is shown, the most common challenges described by parents/caregivers were behaviour problems, problems in communication and repetitive behaviour and movements. Additional challenges mentioned by the parents/caregivers themselves were

related to puberty, the child's future and the presence of tics. In the previous study, the top three challenges in caring for a child with autism reported by parents were also related to difficulties in communication, as well as concerns regarding social interactions and daily living skills (Pejovic-Milovancevic et al, 2018).

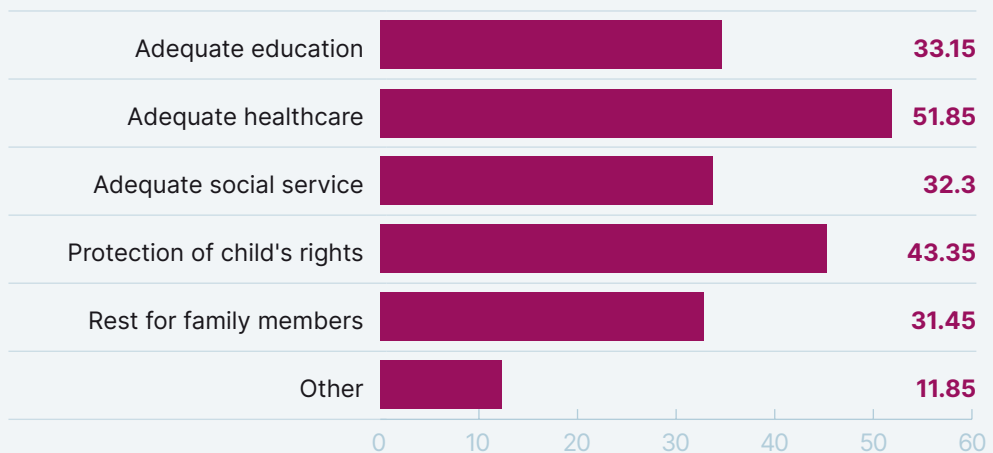


Graph 16. Challenges of parenting a child with ASD.

In the **Graph 17** it is shown that most of the parents reported getting adequate healthcare for their children to be their greatest challenge. Besides that, they were concerned about protection of child's rights and getting adequate education. Parents also listed other challenges they met in getting adequate support for their children and whole family, such as lack of financial support (1.2%), parents' difficulties to find a job or to work fulltime (1.2%), waiting lists for daycare centers (1.2%), etc.

Previous study reported that healthcare and education were recognized among the top three challenges in obtaining support, together with welfare/social support (Pejovic-Milovancevic et al, 2018). In the sample of caregivers in The Republic of North Macedonia, health care services, educational services and social care were also recognized as top challenges in obtaining support (Zorcec and Pop-Jordanova, 2020).

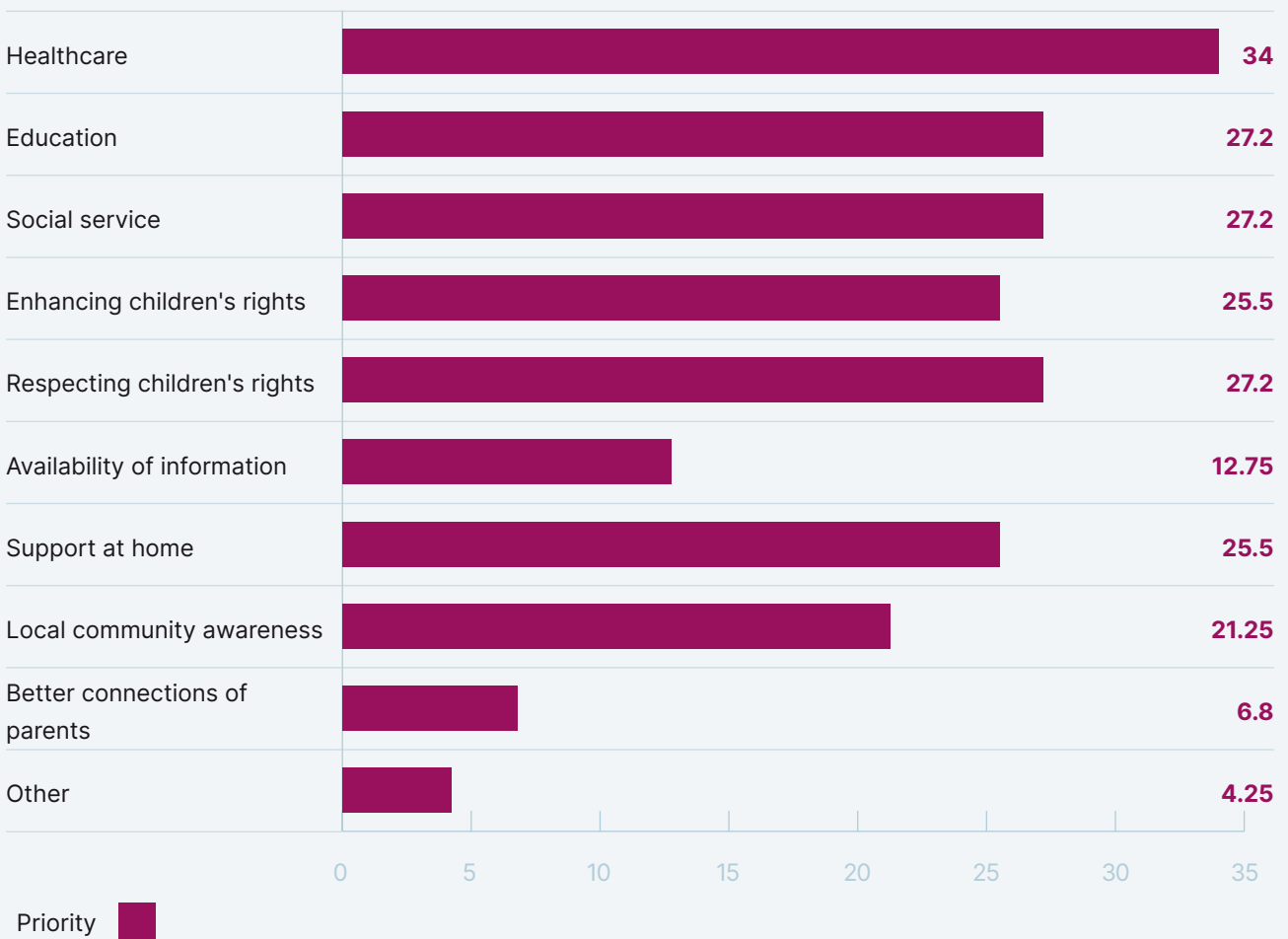
Graph 17. Challenges in providing services for children with ASD.



The majority of parents reported that their priorities were development and enhancement of healthcare services, education, social services, as well as improving children’s rights.

The results are shown in **Graph 18**. The top priorities appear to remain consistent with data obtained by the previous study, pointing out improving rights of the persons with autism, health care services and welfare/ social services as top priorities for families affected by autism in Serbia (Pejovic-Milovancevic et al, 2018).

Graph 18. Priorities, according to parents (%).



DISCUSSION

Although Serbia has largely reformed the laws and public policies in areas relevant to the rights of people with physical and developmental disabilities, these individuals continue to face significant difficulties in terms of access and quality of social, health care and education services, and their families face the problems of poverty and insufficient financial support for additional disability-related expenses (NOOIS, 2017).

The access to healthcare system

The healthcare system is one of the systems with the biggest impact on the well-being of people with physical and developmental disabilities, both because it is the first system in line that can provide support to the individual and the family, and due to the importance of the health care support (NOOIS, 2017). Adolescents and young adults with autism are at risk for developing physical and mental health difficulties through experiencing more lifetime stressors (Moseley et al, 2021).

Results of our research confirm the importance of the healthcare system, since parents highlight doctors from primary medical care and psychiatrists, besides day care workers and parental organizations, as important sources of support.

The majority of them denied that their child is currently involved in treatments other than using pharmacotherapy, which is in line with the data that more than 50% of individuals in the sample are still being treated by psychiatrists. Survey performed in Brazil also indi-

cated that pharmacotherapy, together with behavioral interventions, was most frequently used, while most frequently involved professionals, beside psychiatrists, were neurologists, nutritionists, speech therapists, psychologists and pediatricians (Araripe et al, 2022). Survey performed in Latin America indicate that almost 50% of adults with ASD use pharmacotherapy and most commonly consult a neurologist (Torres et al, 2021).

However, parents and caregivers report difficulties and delays in accessing services, primarily due to the lack of necessary information and long waiting lists. This difficulty appears to be prevalent in the rest of the world as well - a study performed in Brazil indicated that family with children or adolescents with ASD face significant barriers in accessing services, among which long waiting lists, the absence of services and treatments and their cost were most frequently mentioned (Araripe et al, 2022), while results from Latin America also confirmed that adults with ASD face significant barriers in accessing healthcare and other services (Torres et al, 2021).

Meeting support needs

Family members providing care for an individual with ASD are often exposed to a large amount of stress as a result of the complex care and are often faced with the individual's difficulties in functioning, which requires long-term support and assistance (Rivers et al, 2003; Eisenhower et al, 2005). ASD represents a major obstacle in achieving the full parental role and is a source of constant stress for parents, both due to communication difficulties and because of the poorer adaptability of children with ASD.

The guilt and the feeling of inefficiency in the parental role, the environmental stressors, relationships with the partner, extended family, friends and the financial situation are the most common sources of parental dissatisfaction.

It has been pointed out that parents of children with ASD are faced with more pronounced psychosocial and economic stressors compared to parents of children who have other forms of developmental and physical disabilities (Bristol et al, 1988; Montes et al, 2008). The majority of the interviewed caregivers in our sample admitted occasional frustration in an effort to obtain services for their child in the past year. The increased demands of parenting could also have socioeconomic and professional consequences - the majority of caregivers had to quit working or start working part time, while almost half of them have met financial difficulties.

The difficulties, uncertainties, the need for continually adapting, the fact that the entire family is affected requires a constant understanding, support and educational work of all professionals working with children and youth with this problem and their families. In this sense, a form of counseling for better psychosocial adaptation is needed for every family, i.e. for all parents. The results presented in this report suggest that only a minority of parents received education on their children's needs and parenting challenges. Often, due to focus on working with children, experts would neglect the parents, and they are the ones who take responsibility and implement most of the treatment, both physical and psychological, so relatively little can be done for the child without cooperation with parents. That is why it is necessary to motivate parents to recognize the potentials and abilities of their children, instead of putting the emphasis on impairments and deficits, in order to enable them to develop in the direction of the greatest possible independence.

Treatment of ASD in childhood involves a family-oriented approach, considering the needs of the family as a whole, and not just the needs of a child with ASD.

Parents and caregivers need to be encouraged to express their needs for concrete emotional support. This requires them being empowered with knowledge and skills for overcoming stress, having available information, providing services and developing a system of referral to higher level institutions.

Information provision

Our data indicates that the majority of parents receive the information from experts involved in their child's care, while about half of the parents also turn to the Internet and to other parents looking for information. GP/pediatrician and teachers are only recognized as a source of information by a minority of parents.

Numerous studies show that parents were more satisfied when they received the information they requested about their child's condition on time, i.e. when they had the opportunity during the assessment process and diagnostics, and especially after the diagnosis was set, to ask the team of experts questions, or to receive written material with additional necessary information (Ministries of Health and Education of New Zealand, 2008; Bitsika, 1999; Law et al, 2001). In addition to providing information closely related to the nature and manifestation of ASD in the child, it would be necessary to provide information, i.e. sources where the information can be obtained, on the available interventions and measures necessary for comprehensive support to children and the family (services from the social protection and education systems) (Pain, 1999; Whitaker, 2002). When providing information, it is necessary to take into account the age of the child with ASD, but also the cultural and educational level of the family.

Support systems

INCLUSION IN EDUCATION SYSTEM AND TRANSITION PLANNING

The education system is recognized as a valuable resource in providing continuous, easily accessible support to both the child and the family.

Inclusion of children in the system of early education is considered one of the important conditions for identifying children at risk and for early interventions (Strategy on the Development of the Education System in Serbia until 2020, 2012).

Professionals from different systems who are in contact with the family should encourage and support the family to place the child in the education system in a timely manner. Inclusive education is a strategic commitment and a legal obligation of the education system in the Republic of Serbia (Law on the Foundations of the Education System, 2013). As a rule, children with ASD are educated in regular groups and classes, and only when it is in the best interests of the child, according to the Inter-sectoral Commission's (ISC) assessment and with the consent of parents, they are educated in the developmental group of the preschool institution or in a school for education of students with developmental and physical disabilities (Krstic et al, 2016). In our sample the majority of participants graduated primary or secondary school. Our data indicates that the majority of participants used additional educational assistance in the past, while less than 30 percent of them still use those services.

For a child with ASD who needs additional support due to developmental difficulties and for other reasons, the pre-school institution or school is responsible for eliminating the physical and communication barriers and will adopt an individual educational plan (Rulebook on Detailed Conditions for Establishing Priority for Enrolment of Children in a Preschool Institution, 2011).

The team for provision of additional support to a child/student, which consists of: parent, preschool/school teachers, professional associate, personal assistant/pedagogical assistant and, if necessary, a person who knows the child well and who the parent trusts, develops the individual education plan (IOP) based on the pedagogical profile (Rulebook on Additional Educational, Health and Social Support for Children and Stu-

dents, 2010). When the child needs additional support that is also requiring additional financial resources, an ISC procedure can be initiated to assess the needs for additional educational, health care and social support to the child. The school is required to initiate the procedure before adopting the individual educational plan according to the adjusted curriculum (Zlatarovic and Mihajlovic, 2013).

Intersectoral cooperation needs to provide compatible and coordinated support plans for the child and the family from various systems involved in providing support.

Planning the transition of the child from one institution to another or to the next level of education contributes to a faster and more successful adaptation and enables progress in learning and development.

A child with autism should be provided with continuity of socialization, social and emotional support from the children they have established contacts with, provided with inclusion and participation in activities.

Transition activities involve teaching the child important skills for independent functioning in the new environment, along with helping teachers in the new educational environment to understand the needs of the child and make reasonable adjustments in the learning and developmental environment focused on the welfare, inclusion, participation and progress of the child. Involving peers in the process of support to transition, in addition to facilitating it, contributes to development of positive peer relationships in school.

It is important to plan the support for the child and family so that it is as discreet as possible, in order to avoid additional labelling of the child. Institutions have the obligation to involve parents in the process of exchanging information about the child (Zlatarovic and Mihajlovic, 2013).

Students with ASD are also provided support when taking the final exam. In accordance with the individual educational plan, they are entitled to: taking the exam under special conditions, adjusting the existing tests to

the specific needs of the child or development of special tests in accordance with the adjusted educational standards. A student with ASD is enrolled in secondary school after completing the final exam in the special procedure and based on the referral from the District Enrollment Commission, as a measure of achieving full equality in exercising the right to education. The procedure depends on the cognitive status of ASD students.

For high functional students, only specific settings need to be provided (less students around, more quiet place and str). For moderate and difficult ASD finals exam is planned in accordance with IRK recommendations. Young people with ASD also have the right to support when enrolling in university.

SOCIAL SUPPORT

“Every individual and family in need of social assistance and support in order to overcome the social and life difficulties and create the conditions for meeting the basic living needs has the right to social protection, in accordance with the law.

The rights to social protection are met by provision of social protection services and financial support” (Law on Social Protection, 2011).

Families with children with disabilities (hereinafter: families with CwD) are among the most vulnerable beneficiary groups in the social protection system (hereinafter: SPS), not only because of the child’s difficulties which require additional family strain, but also because of the need for support that is long lasting, continuous, comprehensive and that requires coordination of various sectors, services, institutions and organizations. Children with ASD are classified into the group of children with disabilities.

If families do not have support services available, the risk of exhaustion and burnout of parents increases, as well as the risk from neglect, abuse and separation of children from the family.

The parents of children with autism consistently report that they need additional social support (Hall, 2012). Social support may be helpful for caregivers of persons with ASD in alleviating demands, stress and burden, and it might be classified into informal social support network, including supports that are derived from personal relations – family, friends etc. and are not paid by either families or governmental funds and formal social support, which includes paid services (examples such as speech therapy, social work, respite care) (Marsack-Topolewski, 2020).

The Center for Social Work (hereinafter: CSW), as the key institution for provision of the social, family-law and guardianship protection, decides on the exercise of the rights and use of services aimed at the child and family (Law on Social Protection, 2011; Family Law, 2015). Cooperation of various systems (social protection, health care and education systems) is necessary in identifying families with children with disabilities who need additional support to overcome the problems they are facing. That is why it is important for professionals in other systems to know the mandate of the services and institutions in the SPS, as well as the rights, measures and services that this system provides to vulnerable families and children.

Parents and caregivers of ASD can get all the information in the Center for Social Work about the rights and services within the competence of the center itself, but also about those provided by other bodies or organizations. The most common types of assistance that CSW provides to families with ASD are financial benefits, primarily the disability-related support and increased support, assistance for training for work, special cash benefit for non-working parent, etc. Although various forms of financial assistance are certainly important for economic empowerment of the family, families with ASD also need other forms of support and appropriate services to preserve or improve their functioning.

For families with children with ASD, who are particularly at risk of social isolation, inclusion of appropriate assistance and expansion of the social support network is of utmost importance.

The focus in the social protection system is on developing new services that empower the family, support the child's stay in the family and encourage their social inclusion.

In addition to intensive family-oriented services, there is also significant support from less intensive social services that the family can rely on as long as there is a need for a specific type of support, such as: day care, domestic help for families with children with disabilities, respite service, child's personal assistant, shared care, etc. (Rulebook on Conditions and Standards for Social Protection Services, 2013). Each of these services has its place and role in the range of services that are in the function of the support to ASD. While the majority of parents in our sample (68%) indicated that their child is not attending a daily care center (DCC), those whose child was involved in DCC pointed out the heterogeneity of groups, lack of activities, lack of staff, insufficient funds, short working hours, inadequate space and large groups as the main issues.

All types of support that families with children with autism spectrum disorder achieve in the social protection system should aim at developing the potential of the child and his or her active involvement in the community, empowering the family and developing parental capacities so that the family is good enough for the growth and development of children, and at sensitization of the society and the inclusion of the social support network. This prevents burnout of the family, social isolation and separation of the child from the family, and respects his or her best interests – to grow safely and securely in the family environment.

Community-based support

In addition to the support from the nuclear and extended family, formalized forms of health care, educational and social support, parents and caregivers of children with ASD can also require support from other sources within the community. For example, the primary goal of “self-help groups”, which are voluntary organizations, is to provide social support and the necessary information and to advocate for the benefit of the beneficiaries. These groups can help parents cope with challenges in establishing diagnosis and help them not feel lonely in that process (Taylor et al, 1999; Troyb et al, 2016; Steinhausen et al, 2016).

ASD affects all aspects of the child's and his or her family's life, so the importance of social support and the existence of networking of families with the same problems is important (Eaves and Ho, 2004; Gregor and Campbell, 2001; Kennedy et al, 2004; Rivers and Stoneman, 2003; Eisenhower et al, 2005).

Furthermore, adults with autism are at risk for facing diminished social support and experiencing greater loneliness (Moseley et al, 2021). Individuals with comorbid autism and severe ID are considered to be a particularly vulnerable population for poor community inclusion (Gray et al, 2014). Informal social support is important for absorbing the stress in the family of a child with autism (Troyb et al, 2016; Steinhausen, 2016).

Associations have various informal forms of support, such as help line – reliable service run by the staff trained for ASD, counseling work, family assistant, educational camps, etc.

CONCLUSIONS AND RECOMMENDATIONS

Involving subjective experiences of persons with autism and their family members in shaping service provision, aimed at also recognizing strengths rather than only focusing on the impairments, as well as the broader change in societal attitudes, including policymakers, professionals, educators, families and persons with ASD in pursuit of fighting discrimination and stigma is the strategy of great importance in providing support for people with ASD (Han et al, 2021).

The development and enhancement of healthcare services, together with education, social services and improving children's rights remains among top priorities within the framework of support services.

In addition to information support, parents should also receive psychological support through group support/meetings, and medical workers working with children should involve parents in interventions, train them for similar treatment at home, and work with parents to overcome the existing personal problems/dilemmas, i.e. work on empowering parents. Experts should have in mind that parent care is child care as well.

Parents and caregivers of children with ASD need to be provided with the continuous flow of information and assistance in understanding the diagnosis and with empowerment in the decision-making process for choosing interventions.

Bidirectional cooperation between professionals and parents is essential for creating and enhancing the environment's understanding and support for families of persons with ASD.

It is of utmost importance to improve protocols and to standardize procedures for effective support throughout the life course and in particular during adolescence and youth.

It is necessary to introduce a family-oriented approach (expanding the focus of interest and work from the person to the person and family, actively involving parents in care, and if necessary, providing support to the child from birth), to move from medical to bio-psycho-social model in the approach to persons with developmental disabilities, as well as intensifying promotional and preventive action in the community.

It would be very important to intensify support for vulnerable children/persons and families, through gaining a better insight into the health and development needs of the community, increasing the coverage of hard-to-reach populations, primarily through field work and providing intensive family support.

Professionals should consider the context of the family with the child with ASD, and also consider the available informal support systems that they find useful and effective.



It would be of utmost importance if the reform of Labor Law would include special circumstances for parents with children with disabilities in terms of possible working hours adjustments, or flexible working arrangements in general.

Parallel, there are needs to strengthen the professional capacities of all employees in the health, educational and social protection systems by introducing them into the curriculum at faculties, as well as through continuous education, new content on early child development, as well as modern work methods in the field of early interventions along with intervention for youth and adults with ASD. For example, education of non-medical staff included in the mental health system (psychologists, defectologists) of group support interventions for both youth with ASD as well as their caregivers would be of great importance, since it could be efficient for the families with ASD, as well as for the health system. That, however, would require additional staff as well as additional resources for their education. A group for young persons with ASD has been established at the Faculty for special education and rehabilitation in 2019; similar actions are needed across the country.

It is necessary to better connect the support systems and to integrate them through joint activities and coordinated work, where the person with ASD and his family are at the center of all activities.

Each person with ASD should have a team in the pediatric services which should prepare the person and the family for transition into adult services, also consisting of pre-defined teams. The pediatric and the adult

team should be more adequately connected so that the transition would be as less problematic as possible for families involved. A person in both teams (for example a defectologist or a social worker) should be the designated coordinator of the process.

In order to provide better understanding of needs as well as insight into what is valuable for families with young persons with ASD, we need to increase investments in research, which would direct the development of both health and other systems in the comprehensive support of persons with ASD.

The next step is the mapping of the nation-wide existing support network, which might create insight into the most urgent needs of families with persons with ASD throughout the country. Also, studies of the efficacy of the existing programs are needed as well, to potentially improve the actions already being done in our country.

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