TYPES OF TREATMENTS USED BY PARENTS OF CHILDREN WITH AUTISM

TIPOS DE TRATAMENTOS USADOS POR PAIS DE CRIANÇAS COM AUTISMO

| Bojana Arsić | Ania Gaii ć | Sara Vidoikovi ć | Kristina | Aleksandra Baši ć | Dragana | | | |
|----------------------|---------------------|-------------------------|-------------------------|--------------------------|----------------------|--|--|--|
| University of | University of | University of | Ivanovi ć | University of | Maćešić | | | |
| Belgrade, Faculty | Belgrade, Faculty | Belgrade, | University of | Belgrade, Faculty | Petrovi ć | | | |
| for Special | for Special | Faculty for | Belgrade, | for Special | University of | | | |
| education and | education and | Special | Faculty for | education and | Belgrade, | | | |
| rehabilitation | rehabilitation | education and | Special | rehabilitation | Faculty for | | | |
| bojana.arsic57@g | anjuskagajic@gmail. | rehabilitation | education and | <u>aleksandra@faspe</u> | Special | | | |
| <u>mail.com</u> | <u>com</u> | <u>saravidojkovic96</u> | rehabilitation | r.bg.ac.rs | education and | | | |
| | | @gmail.com | <u>ivanovic.kristin</u> | | rehabilitation | | | |
| | | | <u>aa@gmail.com</u> | | <u>macesicd@yaho</u> | | | |
| <u>o.com</u> | | | | | | | | |
| Received: 24/11/2021 | | Accepted: 01/12/2021 | | Published: 01/12/2021 | | | | |
| | | | | | | | | |

Abstract: There is a large number of treatment types offered to parents of children diagnosed with autism spectrum disorders (ASD), but they are particularly vulnerable to the promoters of pseudoscience, which can lead to the use of ineffective types of treatment. This study represents an attempt to document the types of treatments used by parents of children with ASD in the Republic of Serbia. Secondary aim was to determine if certain parent or child characteristics influenced the types of treatments used. Modified version of survey constructed and conducted by Green, et al. (2006) was used. Nearly all (n=85) of the 86 treatments listed in our survey were being currently used or used in the past by at least one parent and the most commonly used treatment is speech and language therapy. The treatments were grouped into ten categories and the most commonly used is other treatments (80.6%), followed by standard therapies (79.2%) and vitamin supplements (65.3%). It is also of great importance to educate the parents of children with ASD about evidence-based treatments and on how to distinguish them from treatments that do not have empirical basis. Suggestions for this were given, limitations and future research implications were discussed.

Keywords: Autism spectrum disorders. Treatment. Parents. Survey.

Resumo: Há um grande número de tipos de tratamento oferecidos aos pais de crianças com diagnóstico de transtornos do espectro do autismo (TEA), mas eles são particularmente vulneráveis aos promotores da pseudociência, o que pode levar ao uso de tipos de tratamento ineficazes. Este estudo representa uma tentativa de documentar os tipos de tratamento usados por pais de crianças com TEA na República da Sérvia. O objetivo secundário era determinar se certas características dos pais ou filhos influenciavam os tipos de tratamento usados. Versão modificada da pesquisa construída e conduzida por Green, et al. (2006) foi usado. Quase todos (n = 85) dos 86 tratamentos listados em nossa pesquisa estavam sendo usados atualmente ou usados no passado por pelo menos um dos pais e o tratamento mais comumente usado é a terapia da fala e da linguagem. Os tratamentos foram agrupados em dez categorias e os mais utilizados são outros tratamentos (80,6%), seguidos das terapias convencionais (79,2%) e suplementos vitamínicos (65,3%). Também é de grande importância educar os pais de crianças

com TEA sobre os tratamentos baseados em evidências e como diferenciá-los de tratamentos que não têm base empírica. Foram dadas sugestões para isso, as limitações e implicações de pesquisas futuras foram discutidas.

Palavras-chave: Transtornos do espectro do autismo. Tratamento. Pais. Enquete.

I. Introduction

Individuals with autism spectrum disorders (ASD) exhibit impairments in communication and reciprocal social interaction and a pattern of restricted, repetitive repertoire of interests and behaviors (American Psychiatric Association, 2013, according to Gajić et al., 2021). Unfortunately, little remains known about the etiology of this disorder (Newschaffer et al., 2007) and because of this, families of children with ASD are particularly vulnerable to the promoters of pseudoscience in the area of treatments offered to their children (Smith & MacDonald, 2017). This can lead to the use of ineffective types of treatment that can consequently exhaust families financial resources, prolong the time for getting effective early intervention services, or even be harmful to the child's health and wellbeing.

There is a large number of treatment types offered to parents of children diagnosed with ASD and treatments can be divided into three groups. Ones with proven benefits for the child, ones with no proven benefits and ones that have possible benefits, but still need more research (Medavarapu et al., 2019). The only treatments that have proven benefits are Applied Behavioral Analysis (ABA) interventions, as well as some symptomatic treatments (Medavarapu et al., 2019). ABA is a branch of psychology that is focused on modification of behaviors that will improve the quality of a person's life (Cooper, Heron & Heward, 2007; Miltenberger, 2003) and it has been used successfully to treat aberrant behaviors in people with ASD (Matson, Mahan & Lo Vullo, 2009). Even though some treatment types have proven to be ineffective, many of these continue to be promoted by some clinicians (Green et al., 2006) and consequently being used by some parents as a treatment type for their child.

This study represents an attempt to document the number and types of treatments used by parents in the treatment of their children diagnosed with ASD in the Republic of Serbia. Secondary aim was to determine if certain parent or child characteristics influenced the number and types of treatments used.

II. Materials and methods

2.1. Survey development

For making a list of the treatments used by parents of children diagnosed with ASD, we used a survey constructed by Green et al. (2006). Some of the interventions the original authors used in their survey were not included, because many of those treatments are not offered in the Republic of Serbia. Some were added, even though they were not present in the original survey, because they are highly used in this region. It is important to state that we changed the names of some medications because they are listed under different names in our country. Types of treatment eliminated from the original survey, or added in our survey are presented in *Table 1* in alphabetical order.

| Treatments excluded from the original survey | Treatments added to our survey |
|---|--------------------------------|
| Adderall | Acupuncture |
| Antihistamine | Aminoacids |
| Azrin toilet training | Animal assisted therapy |
| Bethanechol | Antibiotics |
| Bolles sensory learning method | Bensedin |
| Buspar | Bioenergy therapy |
| Clonidine | Bromazepam |

| Table | 1 | _ ′ | Treatments | added | or | excluded | from | the | original | survey |
|-------|---|-----|------------|-------|----|----------|------|-----|----------|--------|
|-------|---|-----|------------|-------|----|----------|------|-----|----------|--------|

Rio de Janeiro, Brasil

| Chlonopin | Calcium |
|-----------------------------|---|
| Clathration | Concerta |
| Conductive education | Essential acid fats |
| Cylert | Hrono diet |
| Depakote | Hyperbaric chamber |
| Dexedrine | Hyppotherapy |
| Dilantin | Individual psychotherapy sessions |
| Discrete trial training | Individual treatments with special educator |
| Eden program | Lexilium |
| Fast forward therapy | Meomarte method |
| Gentle teaching method | MMS drops / CD protocol |
| Giant steps program | Naltrexone |
| Hagashi program | Namecheck protocol |
| Inderal | Occupational therapy |
| Integrated movement therapy | Physical therapy |
| Interactive metronome | Propranolol |

Rio de Janeiro, Brasil

| Irlen Lenses method | Psychomotor reeducation | | | | |
|-----------------------|---|--|--|--|--|
| Joint action routines | Stem cell therapy | | | | |
| Leap method | Visitations to individuals with supernatural powers | | | | |
| Lindamood bell | Visitations to religious institutions | | | | |
| Options program | Vitamin B | | | | |
| Osteopathy | | | | | |
| Pepcid | | | | | |
| Pyridoxine | | | | | |
| Rapid prompting | | | | | |
| Reduced L-glutathione | | | | | |
| Rolfing therapy | | | | | |
| Secretin | | | | | |
| SIBIS system | | | | | |
| Sporanox | | | | | |
| Tenex | | | | | |
| Transfer factor | | | | | |

Rio de Janeiro, Brasil

| Vagal nerve stimulation | |
|-------------------------|--|
| Valium | |
| Van diju approach | |
| Vancomycin | |
| Visual schedules | |
| Watsu therapy | |

The final survey included 86 treatments and we grouped them into several categories. The categories include: standard therapies, relationship-based treatments, physiological treatments, skill based treatments, combined programs, vitamin supplements, alternative diets, detoxification treatments, medications and other types of treatment. For each treatment type, the parents would state if they use this type of treatment, if they have used it in the past but not currently and if they have never used it. In the last part of the survey, we included one openended question regarding any type of treatment used by the parents that was not listed in our survey, so the parents could write it.

2.2. Survey distribution

The survey was distributed to parents via parental support Facebook groups. The description of the survey stated that the survey is exclusively for parents who have children diagnosed with ASD. The survey description provided information about the study and it was stated to the parents that their involvement is voluntary and anonymous. After a month, the complete set of submissions was exported into a software package SPSS IBM statistics for further data analysis.

2.3. Sample

2.3.1. Respondent characteristics

A total number of parents who filled out the questionnaire was 73, 66 female (90.4%) and 7 male (9.6%). The majority of the parents (29 of them) indicated high school as their highest obtained education level (39.7%), 24 parents have faculty degree (32.9%), 11 parents have completed post-secondary education (15.1%), six parents obtained master's degree (8.2%), only two parents obtained doctoral level degree (2.7%), while only one parent has completed only elementary school (1.4%).

2.3.2. Characteristics of respondents' children

The sex of the children for whom the survey was completed included 63 male (86.2%) and 10 female (13.7%), which is expected, because of the predetermined sex distribution determined by Center for Disease, Control and Prevention (CDC, 2014).Due to the relatively small number of girls in the sample, the data for both sexes was combined for analyses.

Parents were asked to indicate the type and severity of their child's disability by indicating if the child had a diagnosis of Asperger's syndrome, high functioning ASD (if the child communicated) and low functioning ASD (if the child did not have a way of communicating). In total, five parents said that their child has Asperger's syndrome (6.8%), 28 were said to have high functioning ASD (38.4%) and 40 were said to have low functioning ASD (54.8%).

Children in the 0-5 age group comprised 34.2% of the sample (n=25), 22 children were in the 6-10 year old age group (30.1%), 14 children comprised the 11-14 age group (19.2%), six children were in 15-20 year old age group (8.2%) and the remaining six children were 21 years old or older (8.2%).

The number of children distributed by severity of ASD was examined for each of the five age groups, as shown in *Table 2*.

| Table 2 – Distribution by age group and severity of ASD | | | | | | | | |
|---|---------|---------------------|----|----------------------|----|---------------|--|--|
| Age group | | Severity of ASD | | | | | | |
| | Asperge | Asperger's syndrome | | High functioning ASD | | actioning ASD | | |
| | Ν | % | Ν | % | N | % | | |
| 0-5 | 1 | 20% | 8 | 28.5% | 16 | 40% | | |
| 6-10 | 1 | 20% | 9 | 32.1% | 12 | 30% | | |
| 11-14 | 1 | 20% | 5 | 17.8% | 8 | 20% | | |
| 15-20 | 2 | 40% | 2 | 7.1% | 2 | 5% | | |
| 21+ | 0 | 0% | 4 | 14.2% | 2 | 5% | | |
| Total | 5 | 100% | 28 | 100% | 40 | 100% | | |

Rio de Janeiro, Brasil

III. Results and discussion

3.1. Most frequently used treatments

Nearly all (n=85) of the 86 treatments listed in our survey were being currently used or used in the past by at least one parent. *Table 3* represents the rank order of treatments in terms of percentage of parents reporting current use, as well as information about each treatment in terms of percentage of parents who used it in the past, or never used it. As shown in Table 3, the most commonly used treatment is speech and language therapy, currently being used by 61.6% of the parents and used by 26% of the parents in the past. The same finding was reported by Green, et al., (2006). After speech and language therapy, the next most commonly used treatments were individual sessions with a special educator (54.8%) which is expected, as it is common for children with ASD to have individual sessions with educators who have a major in special education and rehabilitation of people with intellectual disabilities. Next most commonly used treatments are vitamin C supplements (49.3%), magnesium supplements (49.3%), vitamin B supplements (46.5%), probiotics (46.5%), visitations to religious institutions (43.8%), sensory integration (42.5%) and hugging therapy (41.1%). It is concerning that currently the most commonly used treatments are the ones without any empirical evidence.

Table 3 - Rank order of treatments in terms of percentage of parents reporting current use

| Number | Treatment name | | Category | Pe | ercentage | |
|--------|-------------------------------------|-------|------------------------|-------------------|-----------------|---------------|
| | | | | Currently uses | Used in past | Never used |
| 1 | Speech and language therapy | 7 | Standard therapies | 61.6% | 26% | 12.3% |
| 2 | Special educator indivi sessions | idual | Standard therapies | 54.8% | 23.3% | 21.9% |
| 3 | Vitamin C | | Vitamin supplements | 49.3% | 16.4% | 34.2% |
| 4 | Magnesium | | Vitamin supplements | 49.3% | 11% | 39.7% |
| 5 | Vitamin B | | Vitamin supplements | 46.6% | 17.8% | 35.6% |
| 6 | Probiotics | | Medication | 46.6% | 16.4% | 37% |
| 7 | Visitations to relig | gious | Other | 43.8% | 4.1% | 52.1% |

Rio de Janeiro, Brasil

| | institutions | treatments | | | |
|----|---------------------------------|------------------------|-------|-------|-------|
| 8 | Sensory integration | Physiological | 42.5% | 20.5% | 37% |
| 9 | Hugging therapy | Relationship based | 41.1% | 2.7% | 56.2% |
| 10 | Sessions with a psychologist | Skill based | 38.4% | 24.7% | 37% |
| 11 | Social stories | Skill based | 38.4% | 5.5% | 56.2% |
| 12 | Essential fatty acids | Vitamin supplements | 35.6% | 11% | 53.4% |
| 13 | Casein free diet | Alternative diet | 34.2% | 15.1% | 50.7% |
| 14 | Gluten free diet | Alternative diet | 34.2% | 16.4% | 49.3% |
| 15 | Sensory rooms | Physiological | 32.9% | 21.9% | 45.2% |
| 16 | Massage therapy | Other treatments | 32.9% | 8.2% | 58.9% |
| 17 | Essential fatty acids free diet | Alternative diet | 28.8% | 11% | 60.3% |
| 18 | Floortime | Relationship based | 27.4% | 19.2% | 53.4% |
| 19 | Vitamin B6 | Vitamin supplements | 27.4% | 17.8% | 54.8% |
| 20 | Psychomotor reeducation | Standard treatments | 26% | 23.3% | 50.7% |
| 21 | PECS | Skill based | 26% | 17.8% | 56.2% |

22 Yeast free diet Alternative diet 24.7% 67.1% 8.2% 23 Animal assisted therapy Other 24.7% 4.1% 71.2% treatments 24 Aminoacids Alternative diet 5.5% 74% 20.5% 25 Vitamin A Vitamin 19.2% 69.9% 11% supplements 26 Megavitamin Vitamin 19.2% 6.8% 74% supplements 27 Occupational therapy Standard 17.8% 5.5% 76.7% treatments 28 Melatonin Medication 12.3% 69.9% 17.8% 29 Skill based Cognitive behavioral therapy 17.8% 6.8% 75.3% 30 Alternative and augmentative Skill based 17.8% 2.7% 79.5% communication (different communication devices) 31 Calcium Vitamin 17.8% 9.6% 72.6% supplements 32 Visual integration Physiological 16.4% 0% 83.6% 33 Antibiotics Medication 47.9% 16.4% 35.6% 34 Physical therapy Standard 15.1% 13.7% 71.2% treatments 35 Applied behavior analysis Skill based 15.1% 12.3% 72.6%

Isagoge, v. 1, n. 6, p. 01-27, 2021, ISSN 2763-7123

Rio de Janeiro, Brasil

| 36 | Homeopathy | Other | 13.7% | 17.8% | 68.5% |
|----|-------------------------------|------------------------|-------|-------|-------|
| | | treatments | | | |
| 37 | Facilitated communication | Skill based | 13.7% | 1.4% | 84.9% |
| 38 | Auditive integration | Physiological | 12.3% | 2.7% | 84.9% |
| 39 | Music therapy | Standard treatments | 11% | 16.4% | 72.6% |
| 40 | Dance therapy | Other treatments | 11% | 2.7% | 86.3% |
| 41 | TEACCH | Combined program | 9.6% | 4.1% | 86.3% |
| 42 | Weighted blanket | Other treatments | 9.6% | 9.6% | 80.8% |
| 43 | Prolonged breastfeeding | Relationship based | 8.2% | 0% | 91.8% |
| 44 | Neurofeedback and biofeedback | Physiological | 8.2% | 6.8% | 84.9% |
| 45 | Bioenergy | Other treatments | 8.2% | 15.1% | 76.7% |
| 46 | Hippo therapy | Other treatments | 8.2% | 6.8% | 84.9% |
| 47 | MMS protocol - CD drops | Other treatments | 8.2% | 1.4% | 90.4% |
| 48 | Aromatherapy | Other treatments | 8.2% | 4.1% | 87.7% |

Rio de Janeiro, Brasil

| 49 | Nemechek protocol | Other treatments | 6.8% | 11% | 82.2% |
|----|---|------------------------|------|------|-------|
| 50 | Chelation | Detoxification | 6.8% | 0% | 93.2% |
| 51 | Hyperbaric chamber | Detoxification | 5.5% | 6.8% | 87.7% |
| 52 | Propranolol | Medication | 5.5% | 1.4% | 93.2% |
| 53 | Risperdal | Medication | 5.5% | 8.2% | 86.3% |
| 54 | Doman | Combined programs | 4.1% | 0% | 95.9% |
| 55 | Dimetilglicin | Vitamin supplements | 4.1% | 4.1% | 91.8% |
| 56 | L glutamine | Vitamin supplements | 4.1% | 6.8% | 89% |
| 57 | Ritalin | Medication | 4.1% | 2.7% | 93.2% |
| 58 | Immunoglobulin | Medication | 4.1% | 2.7% | 93.2% |
| 59 | Haldol | Medication | 4.1% | 2.7% | 93.2% |
| 60 | Lithium | Medication | 4.1% | 4.1% | 91.8% |
| 61 | Neural therapy | Physiological | 2.7% | 0% | 97.3% |
| 62 | Visitations to individuals with superpowers | Other treatments | 2.7% | 11% | 86.3% |
| 63 | Concerta | Medication | 2.7% | 5.5% | 91.8% |

Rio de Janeiro, Brasil

| 64 | Thorazin | Medication | 2.7% | 2.7% | 94.5% |
|----|----------------------|-----------------------|------|-------|-------|
| 65 | Acupuncture | Other treatments | 2.7% | 1.4% | 95.9% |
| 66 | Zoloft | Medication | 2.7% | 5.5% | 91.8% |
| 67 | Tegretol | Medication | 2.7% | 6.8% | 90.4% |
| 68 | Xanax | Medication | 2.7% | 1.4% | 95.9% |
| 69 | Bromazepan | Medication | 2.7% | 2.7% | 94.5% |
| 70 | Bensedin | Medication | 2.7% | 2.7% | 94.5% |
| 71 | Nystatin | Medication | 2.7% | 15.1% | 82.2% |
| 72 | Naltrexone | Medication | 2.7% | 0% | 97.3% |
| 73 | Meomarte | Relationship based | 1.4% | 1.4% | 97.3% |
| 74 | Feingold diet | Alternative diet | 1.4% | 0% | 98.6% |
| 75 | Stem cell therapy | Other treatments | 1.4% | 1.4% | 97.3% |
| 76 | Craniosacral therapy | Other treatments | 1.4% | 1.4% | 97.3% |
| 77 | Chrono diet | Alternative diet | 1.4% | 1.4% | 97.3% |
| 78 | Prozac | Medication | 1.4% | 0% | 98.6% |

Rio de Janeiro, Brasil

| 79 | Dolphin therapy | Other treatments | 1.4% | 0% | 98.6% |
|----|---------------------------|---------------------|------|------|-------|
| 80 | Paxil | Medication | 1.4% | 0% | 98.6% |
| 81 | Diflucan | Medication | 1.4% | 4.1% | 94.5% |
| 82 | Pentoxifilin | Medication | 1.4% | 0% | 98.6% |
| 83 | Anafranil | Medication | 1.4% | 1.4% | 97.3% |
| 84 | Clozapine | Medication | 1.4% | 0% | 98.6% |
| 85 | Electroconvulsive therapy | Skill based | 0% | 1.4% | 98.6% |
| 86 | Lexilium | Medication | 0% | 0% | 100% |
| | | | | | |

Rio de Janeiro, Brasil

The study conducted by Kuriyama et al. (2002) with the goal of examining the effects of vitamin B and magnesium supplementation did not demonstrate any difference in improving any of the ASD-related symptoms compared to the placebo group. Same refers to the article published by Adams & Holloway (2005) regarding vitamin C supplementation. Therefore we can determine that the high frequency of supplementation use is common in our region.

The social changes that occurred in the Republic of Serbia in the past decades are believed to have an effect on the discontent of its citizens about the political situation and it is believed that this resulted in the newly popularization of religion (Blagojević, 1993). Religion has become of great importance in the majority of people's lives (Blagojević, 2006) and therefore it is not surprising that parents of children with ASD turn to it for consolation and use it as a form of treatment, even though it cannot be considered a treatment modality.

Even though sensory integration therapy has been a popular treatment form for children diagnosed with ASD all over the world, none of the studies conducted regarding its effectiveness have proven its benefits (Bettison, 1996; Case-Smith & Bryan, 1999; Rimland & Edelson, 1995). When it comes to hugging therapy, perhaps the parents thought that it refers

to hugging their children in general, therefore this can be the explanation for the high frequency of this particular treatment. Hugging therapy was a popular form of treatment in the past, when it was believed that ASD is a result of a defective bond between a child and the mother. The philosophy of it was that the mother could prevent the symptoms if she provided physical contact to the child, but up to this date, there is no research published regarding this type of treatment efficiency, same as for the use of probiotics (Medavarapu et al., 2019).

More than a third of the sample currently receive sessions with a psychologist (38.4%), social stories (38.4%), essential fatty acids as a supplement (35.6%), casein free diet (34.2%), gluten free diet (34.2%), sensory rooms (32.9%) and massage therapy (32.9%).

It is mandatory for each school to have a school psychologist (Maksić & Đurišić-Bojanović, 2017) and since the inclusive education act from 2006, the majority of children with developmental disabilities were included in regular school systems (Stanković Đorđević, 2013). Most of the children with some form of disability have regular psychological sessions in the school environment, so perhaps this was the reason why there was a high percentage of parents who listed these sessions as a treatment used regularly by their child. Social stories are the only one of the 15 most commonly used treatments that have proven benefits for children with ASD, if they are implemented correctly, being individualized for each child in terms of their ability to understand them and if they are introduced with the appropriate teaching method (Saad, 2016).

Even though essential fatty acids are used by over a third of our sample, there is insufficient scientific evidence in order to claim that they are useful in treatment of children diagnosed with ASD (Bell et al., 2004; Politi et al., 2008). Elder et al. (2006) conducted a longitudinal research with the aim of examining the effectiveness of combined gluten-free and casein-free diet on relieving the ASD symptoms and proved that there was no difference in ASD related symptoms between experimental and control group, therefore making these alternative diets not an effective treatment modality for children with ASD, despite advocates of the contrary.

Sensory rooms were listed in our survey as a specific treatment, other than sensory integration therapy, because the majority of parents use it independently, meaning the child's stay in a sensory room as a treatment type, but it has the same ineffectiveness as stated above. All of the studies that were conducted with the aim of examining the effectiveness of massage therapy on behavioral, adaptive and social skills of children with ASD are considered to be biased and were conducted within a small sample, inadequate control and lack of follow up (Lee et al., 2010).

3.2. Categories of treatments used

The treatments that were being currently used by parents of children with ASD were grouped in the mentioned 10 categories, and *Table 4* represents the rank order of percentage of parents indicating current use of each treatment category. As shown in *Table 4*, the most commonly used treatment category is other treatments, with 80.6% of the respondents indicating current use of any of the treatments listed in that category, followed by standard therapies (79.2%) and vitamin supplements (65.3%).

| Percentage |
|------------|
| 80.6% |
| 79.2% |
| 65.3% |
| 68.1% |
| 61.1% |
| 61.1% |
| 55.6% |
| 54.2% |
| 11.1% |
| 9.7% |
| |

Table 4 - Rank order of percentage of parents indicating current use of each treatment category

Almost all of the categories of treatments were currently used by more than a half of the sample, while combined programs and detoxification treatments were used by 11.1% and 9.7% of the sample. This is a positive result, because both of the treatments listed under the detoxification category have no proven benefits for children with ASD (Granpeesheh, et al., 2010; Nelson & Bauman, 2003; Rossignol et al., 2007) and could potentially be harmful to the child's wellbeing (Stevenson et al., 2015). While in the combined treatments category, Doman program is a vastly researched treatment, but majority of the articles published regarding the effectiveness of Doman program on improving some aspects of ASD symptoms are with inadequate research experimental design and without the control group, therefore it cannot be considered evidence based treatment (Aydillah & Rokhaidah, 2018). But it is surprising that TEACCH program has a low frequency of use among parents, considering it is a treatment form with possible benefits for children with ASD (Myers & Johnson, 2007; Ozonoff & Cathcart, 1998; Panerai et al., 2009), therefore we believe that it should be more commonly used among parents of children with ASD.

Table 5 represents the percentage of use for each treatment category by type/severity of ASD. The cumulative percentage represents the total of percentage use for each category listed in *Table 5*. It is also organized by frequency of use listed in *Table 4*. *Table 5* shows that parents who have children with Asperger's syndrome use less treatments, whereas children with high functioning ASD use more treatments from each category and parents who have children with low functioning ASD comprise the majority of those who use the most treatments from each category. The exception is the combined programs category, where parents of children with high functioning ASD and low functioning ASD had the same use rates, but the overall score for application of that treatment category is still lower than others.

| Treatment category | Type/severity of ASD | | | | |
|---------------------|----------------------|----------------------|---------------------|--|--|
| | Asperger's syndrome | High functioning ASD | Low functioning ASD | | |
| Other treatments | 2.8% | 33.3% | 44.4% | | |
| Standard therapies | 4.2% | 34.7% | 40.3% | | |
| Vitamin supplements | 2.8% | 26.4% | 36.1% | | |
| Physiological | 2.8% | 29.2% | 36.1% | | |
| Medication | 4.2% | 23.6% | 33.3% | | |
| Skill based | 1.4% | 27.8% | 31.9% | | |
| Relationship based | 1.4% | 19.4% | 34.7% | | |
| Alternative diet | 1.4% | 19.4% | 33.3% | | |
| Combined programs | 0% | 5.6% | 5.6% | | |
| Detoxification | 0% | 4.2% | 5.6% | | |

Table 5 - Percentage of use for each treatment category by type/severity of ASD

Having a child with ASD can be highly stressful for parents and substantially affect their psychological well-being (Emerson, 2003), because of the prolonged dependency and need for financial support. Even though there are studies that have shown that there is no difference between parental stress level and severity of ASD (Rao & Beidel, 2009), children with low functioning ASD exhibit increased deficits in the areas of social interaction, restricted behavior patterns and pragmatic skills (Mayes et al., 2011), as well as increased hyperactivity and conduct problems (Allik et al., 2006). With that being said, it is expected that parents would be willing to try out several different treatments at the same time. However, using multiple treatments at the same time can lead to compliance problems (Chandler et al., 2018) and it can also disable the possibility of knowing which treatment was effective.

3.3. Additional treatments added by parents themselves

In the open-ended question, where parents could write other treatments that were not included in the survey and that their children took part in, the many of them listed attending school or kindergarten for children with special needs, which cannot be considered a treatment category itself, because according to Individuals with Disabilities Education Act (IDEA, 2004) all children should attend school, regardless of disability.

Some of the parents listed sports activities as a form of treatment, and even though motor skills development is a crucial part of childhood (Barnett et al., 2008; Lubans et al., 2010), sports activities should be a common leisure activity that is a part of every child's development. Knowing that children diagnosed with ASD exhibit significant motor delays compared to typically developing peers (Lloyd et al., 2013; Whyatt & Craig, 2012), perhaps the parents who listed sports activities as a type of treatment referred to it as a way of improving their children's motor skills, coordination and social interaction.

Epilepsy is a common condition that coexists with ASD and a prevalence of epilepsy in people with ASD is 12.1% (Lukmanji et al., 2019) and the therapy for it usually depends on finding the right combination and dosage of medications. It is expected that not all antiepileptic medications were included in our survey, therefore there were some medications that were included by parents themselves, such as Trileptal and Depakine. Same refers to antipsychotic medications, such as Olanzapine, Actawell and Azolar, since they are also commonly used by children diagnosed with ASD (Larson et al., 2017).

Since 65.3% of the sample said that they were using vitamin supplements as a form of treatment for their child, it is not surprising that some parents listed another vitamin supplements that we did not include in the survey, such as iodine supplement, metilfolat, cynk, selen, silver water and fish liver oil. As stated above, vitamin supplements are a non-effective treatment for any of the symptoms related to ASD (Adams & Holloway, 2005; Kuriyama et al., 2002).

Some of the parents indicated that they have been using Tomatis Method as a treatment modality for their children. Several authors examined the effectiveness of the Tomatis Method on certain aspects of ASD related symptoms, but the results showed that there is a lack of improvement (Corbett et al., 2008) and even though some articles showed

some improvement, they are considered to be using an inappropriate test design (Gerritsen, 2008).

There is a critical need to identify children with ASD at a very young age so that they can access evidence-based intervention that can significantly improve their outcomes (Ventola et al., 2006). Since access to high quality treatment for nearly all children diagnosed with ASD is of crucial value, it is important to document the number and types of treatments being used by parents of children with ASD. Data of this type may enable professionals to provide parents with the information needed to make more informed choices about treatment selection and promote evidence-based practice (Green et al., 2006). It is also of great importance to educate the parents of children with ASD about evidence-based treatments (Smith & MacDonald, 2017), such as Applied Behavior Analysis and on how to distinguish them from treatments that do not have empirical basis.

IV. Conclusions

Results of our research indicated that parents primarily chose to take their children to treatments that are not evidence based and it is of crucial value to increase the use of evidence based treatments among parents of children with ASD or children with any type of developmental disability in general. This can be done by expanding knowledge of future and practicing special educators about evidence based treatments, in order for them to decide to expand their education in those areas and not attend seminars and workshops about treatments that are not evidence based. Also, our Faculty curriculum should include evidence based treatments, in order for them to decide to expand their education based. Also, our Faculty curriculum should include evidence based treatments, in order for current students to be educated in that area. Some legal adjustments could also be made so that is not allowed that individuals who offer services to children with ASD use practices that have no proven benefits.

It is of crucial value to determine why parents decide to use vitamin supplements as a form of treatment for their children diagnosed with ASD, since vitamin supplements were the third most commonly used treatment modality, as well as the mostly listed types of treatment by parents themselves in the last open-ended questions part of the questionnaire. It is also important to highlight that none of the treatments that parents listed themselves does not have proven benefits for children with ASD, therefore we emphasize the importance of educating

parents of children with ASD about distinguishing treatments with and without proven benefits.

Future research might address the reasons to why parents decide on using these treatments in the first place, as well as what are the reasons why some of the treatments are not being used anymore, especially for ones with proven benefits. We also believe that the replication of the same research should be conducted in the future on a bigger sample of parents in our country or region, which is also one of the biggest research limitations in our opinion. A replication should also be conducted in different countries as well, in order to see the global differences in parental decision making process. Another limitation of this research is the exclusion of questions regarding family income, because we believe it is partially responsible for making a decision about some treatments. It is of crucial value to conduct a research regarding parental ways of gathering information about treatment types available to them, in order to examine how they get informed about treatments and to determine if those information sources are adequate.

V. Acknowledgements

This paper was realized with the support of the Ministry of Education, Science and Technological Development of the Republic of Serbia, according to the Agreement on the realization and financing of scientific research.

VI. References

Adams, J. B., & Holloway, C. (2004). Pilot study of a moderate dose multivitamin/mineral supplement for children with autistic spectrum disorder. *Journal of Alternative & Complementary Medicine*, 10(6), 1033-1039. <u>https://doi.org/10.1089/acm.2004.10.1033</u>

Allik, H., Larsson, J. O., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and quality of life outcomes*, 4(1), 1-8. <u>https://doi.org/10.1186/1477-7525-4-1</u>

Aydillah, D., & Rokhaidah, R. (2018). Metode Glenn Doman Mening. Care: Jurnal Ilmiah Ilmu Kesehatan, 6(1), 15-25.<u>https://doi.org/10.33366/cr.v6i1.740</u>

Barnett, L. M., van Beurden, E., Morgan, P. J., Brooks, L. O., & Beard, J. R. (2008). Childhood motor skill proficiency as a predictor of adolescent physical activity. *Journal of Adolescent Health*, 44(3), 252–259. <u>https://doi.org/10.1016/j.jadohealth.2008.07.004</u>

Bell, J. G., MacKinlay, E. E., Dick, J. R., MacDonald, D. J., Boyle, R. M., & Glen, A. C. A.
(2004). Essential fatty acids and phospholipase A₂ in autistic spectrum disorders. *Prostaglandins*, *Leukotrienes and Essential Fatty Acids*, 71(4), 201-204.<u>https://doi.org/10.1016/j.plefa.2004.03.008</u>

Bettison, S. (1996). The long-term effects of auditory training on children with autism. *Journal of autism and developmental disorders*, 26(3), 361-374. <u>https://doi.org/10.1007/BF02172480</u>

Blagojević, M. (1993). Jugoslovenski kontekst: sekularizacija I desekularizacija. Gradina.

Blagojević, M. (2006). Current religious changes in Serbia and desecularization. *Filozofijaidrustvo*, (31), 239-253.<u>https://doi.org/10.2298/FID0631239B</u>

Case-Smith, J., & Bryan, T. (1999). The effects of occupational therapy with sensory integration emphasis on preschool-age children with autism. *American Journal of Occupational Therapy*, 53(5), 489-497. <u>https://doi.org/10.5014/ajot.53.5.489</u>

Centers for Disease Control and Prevention (CDC). (2014). CDC estimates 1 in 68 children has been identified with autism spectrum disorder. <u>https://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html?utm_source=Autism+Monthly+-</u>

+April+2014&utm_campaign=April+Autism+Monthly&utm_medium=email

Chandler, R. J., Russell, A., & Maras, K. L. (2019). Compliance in autism: Self-report in action. Autism, 23(4), 1005-1017.<u>https://doi.org/10.1177%2F1362361318795479</u>

Cooper, J.O., Heron, T.E., Heward, W.L. (2007). *Definition and characteristics of applied behavior analysis.* 2nd ed. Prentice Hall, Englewood Cliffs, New York City.

Corbett, B. A., Shickman, K., & Ferrer, E. (2008). Brief report: the effects of Tomatis sound therapy on language in children with autism. *Journal of autism and developmental disorders*, 38(3), 562-566.<u>https://doi.org/10.1007/s10803-007-0413-1</u>

Elder, J. H., Shankar, M., Shuster, J., Theriaque, D., Burns, S., & Sherrill, L. (2006). The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. *Journal of autism and developmental disorders*, *36*(3), 413-420.<u>https://doi.org/10.1007/s10803-006-0079-0</u> Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, *47*(4), 385-399. https://doi.org/10.1046/j.1365-2788.2003.00498.x

Gajić, A., Arsić, B., Bašić, A., Maćešić-Petrović, D., & Zdravković Parezanović, R. (2021). Increasing hairdressing compliance with a child with autism spectrum disorders. *European Journal of Special Education Research*, 7(2), 84-95. <u>http://dx.doi.org/10.46827/ejse.v7i2.3758</u>

Gerritsen, J. (2008). Response to" Brief Report: The Effects of Tomatis Sound Therapy on Language in Children with Autism", July 3, 2007, Journal of Autism and Developmental Disorders. *Journal of autism and developmental disorders*, 38(3), 567.<u>https://doi.org/10.1007/s10803-007-0471-4</u>

Granpeesheh, D., Tarbox, J., Dixon, D. R., Wilke, A. E., Allen, M. S., & Bradstreet, J. J. (2010). Randomized trial of hyperbaric oxygen therapy for children with autism. *Research in Autism Spectrum Disorders*, 4(2), 268-275.https://doi.org/10.1016/j.rasd.2009.09.014

Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27(1), 70-84. <u>https://doi.org/10.1016/j.ridd.2004.12.002</u>

Kuriyama, S., Kamiyama, M., Watanabe, M., Tamahashi, S., Muraguchi, I., Watanabe, T., Hozawa, A., Ohkubo, T., Nishino, Y., Tsubono, Y., Tsuji, I., & Hisamichi, S. (2002). Pyridoxine treatment in a subgroup of children with pervasive developmental disorders.

Developmental medicine and child neurology, 44(4), 283-286.<u>https://doi.org/10.1017/S0012162201232071</u>

Larson, F. V., Wagner, A. P., Jones, P. B., Tantam, D., Lai, M. C., Baron-Cohen, S., & Holland, A. J. (2017). Psychosis in autism: comparison of the features of both conditions in a dually affected cohort. *The British Journal of Psychiatry*, 210(4), 269-275.<u>https://doi.org/10.1192/bjp.bp.116.187682</u>

Lee, M. S., Kim, J. I., & Ernst, E. (2010). Massage therapy for children with autism spectrum disorders: a systematic review. *The Journal of clinical psychiatry*, 72(3), 406-411.

Lloyd, M., MacDonald, M., & Lord, C. (2013). Motor skills of toddlers with autism spectrum disorders. Autism, 17(2), 133–146. <u>https://doi.org/10.1177%2F1362361311402230</u>

Lubans, D. R., Morgan, P. J., Cliff, D. P., Barnett, L. M., & Okely, A. D. (2010). Fundamental movement skills in children and adolescents. *Sports Medicine*, 40(12), 1019–1035. https://doi.org/10.2165/11536850-000000000-00000

Lukmanji, S., Manji, S. A., Kadhim, S., Sauro, K. M., Wirrell, E. C., Kwon, C. S., & Jetté, N. (2019). The co-occurrence of epilepsy and autism: A systematic review. *Epilepsy & Behavior*, 98, 238-248.<u>https://doi.org/10.1016/j.yebeh.2019.07.037</u>

Maksić, S., & Đurišić-Bojanović, M. (2017). Doprinos školskog psihologa primeni principa pozitivne psihologije u razvoju škole [The school psychologist's role in implementing the principles of positive psychology in the development of the school]. *Nastavaivaspitanje*, 66(2), 337-350.

Matson, J.L., Mahan, S., Lo Vullo, S.V. (2009). Parent training: a review of methods for children with developmental disabilities. *Research in Developmental Disabilities*, 30, 961-968.

Mayes, S. D., Calhoun, S. L., Murray, M. J., Morrow, J. D., Cothren, S., Purichia, H., Yurich, K. K. L. & Bouder, J. N. (2011). Use of Gilliam Asperger's disorder scale in differentiating high and low functioning autism and ADHD. *Psychological reports*, 108(1), 3-13.<u>https://doi.org/10.2466%2F04.10.15.PR0.108.1.3-13</u>

Medavarapu, S., Marella, L. L., Sangem, A., & Kairam, R. (2019). Where is the Evidence? A Narrative Literature Review of the Treatment Modalities for Autism Spectrum Disorders. *Cureus*, 11(1). <u>https://dx.doi.org/10.7759%2Fcureus.3901</u>

Miltenberger, R.G. (2003). Introduction to behavior modification: Principles and Procedures. 3rd edition. Wadsworth, New York City.

Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics*, 120(5), 1162-1182.<u>https://doi.org/10.1542/peds.2007-2362</u>

Nelson, K. B., & Bauman, M. L. (2003). Thimerosal and autism?. *Pediatrics*, 111(3), 674-679.<u>https://doi.org/10.1542/peds.111.3.674</u>

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., Mandell, D. S., Miller, L. A., Pinto-Martin, J., Reaven, J., Reynolds, A. M., Rice, C. E., Schendel, D., & Windham, G. C. (2007). The Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health*, 28, 235–258. <u>https://doi.org/10.1146/annurev.publhealth.28.021406.144007</u>

Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of autism and developmental disorders*, 28(1), 25-32. https://doi.org/10.1023/A:1026006818310

Panerai, S., Zingale, M., Trubia, G., Finocchiaro, M., Zuccarello, R., Ferri, R., & Elia, M. (2009). Special education versus inclusive education: the role of the TEACCH program. Journal of autism and developmental disorders, 39(6), 874-882. https://doi.org/10.1007/s10803-009-0696-5 Politi, P., Cena, H., Comelli, M., Marrone, G., Allegri, C., Emanuele, E., & di Nemi, S. U. (2008). Behavioral effects of omega-3 fatty acid supplementation in young adults with severe autism: an open label study. Archives of medical research, 39(7), 682-685.<u>https://doi.org/10.1016/j.arcmed.2008.06.005</u>

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior modification*, 33(4), 437-451.<u>https://doi.org/10.1177%2F0145445509336427</u>

Rimland, B., & Edelson, S. M. (1995). Brief report: A pilot study of auditory integration training in autism. *Journal of autism and developmental disorders*, 25(1), 61-70. <u>https://doi.org/10.1007/BF02178168</u>

Rossignol, D. A., Rossignol, L. W., James, S. J., Melnyk, S., & Mumper, E. (2007). The effects of hyperbaric oxygen therapy on oxidative stress, inflammation, and symptoms in children with autism: an open-label pilot study. *BMC pediatrics*, 7.<u>https://doi.org/10.1186/1471-2431-7-36</u>

Saad, M. A. E. (2016). The Effectiveness of Social Stories among Children and Adolescents with Autism Spectrum Disorders: Meta-Analysis. Online Submission, 5(2), 51-60.

Smith, I. M., & MacDonald, N. E. (2017). Countering Evidence Denial and the Promotion of Pseudoscience in Autism Spectrum Disorder. *Autism Research*, 10(8), 1334-1337. https://doi.org/10.1002/aur.1810

Stanković Đorđević, M. (2013). Obrazovna inkluzija u Srbijii u svetu. [Educational inclusion in Serbia and in the world] In B. Dimitrijević (Ed.) *Развој и ментално здравље – тематски зборник радова* (pp. 141-154). Филозофски факултет Универзитета у Нишу.

The Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §1400 (2004). https://sites.ed.gov/idea/

Ventola, P. E., Kleinman, J., Pandey, J., Barton, M., Allen, S., Green, J., Robins, D., & Fein, D. (2006). Agreement among four diagnostic instruments for autism spectrum disorders in toddlers. *Journal of Autism and Developmental Disorders*, 36(7), 839–847. https://doi.org/10.1007/s10803-006-0128-8

Whyatt, C. P., & Craig, C. M. (2012). Motor skills in children aged 7–10 years, diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(9), 1799–1809. https://doi.org/10.1007/s10803-011-1421-8



www.telosjournals.com.br