

# SOCIAL SUPPORT FOR FAMILIES RAISING CHILDREN WITH AUTISM SPECTRUM DISORDERS

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**Abstract.** The article reviews the issues the families raising children with Autism Spectrum Disorders encounter and the assistance available. The theoretical part presents the concept of Autism Spectrum Disorders and reviews the legal acts regulating family support and the need for social worker's assistance for those families. The disorder usually manifests itself in early childhood, but the symptoms of autism can also appear later when social norms exceed the individual's capabilities. Currently, there is no cure for Autism Spectrum Disorders, but various scientific studies show that it can be facilitated with various treatments.

The research data show that after the child's diagnosis, families received various social support; they were provided with the child's disability and care money, sanatorium treatment, speech therapist services, special kindergarten education services, and psychologist services.

It has also been determined that parents often face problems, such as financial difficulties, disturbed life rhythm, changed family functions, changes in family relationships, stress, and anxiety. It has been revealed that families raising children with Autism Spectrum Disorders lack free psychological counselling, greater financial support and information about autism spectrum disorder in one place. Parents often cannot find work because employers do not create favourable conditions allowing them to align parents' working hours to the working hours of the child's education institution. Parents of children with Autism Spectrum Disorders face social rejection and bullying and lack qualified professionals and the social support necessary. The research participants revealed a particular shortage of social workers' services, organisation of children's occupation, free therapy options, temporary respite services, and qualified specialists who would be ready to work with children with Autism Spectrum Disorders.

**Keywords:** Autism Spectrum Disorders, Child Autism, Atypical Autism, Asperger's Syndrome

## Introduction

Autism Spectrum Disorder (hereinafter referred to as ASD) is a non-specific disorder that may occur because of biological and genetic causes. It is a lifelong developmental disability that has a notable impact on the emotional state of the family and causes significant financial costs to both society and the family raising the child. According to the International Classification of Diseases (ICD-10) (2021), the term ASD includes Childhood Autism, Atypical Autism, and Asperger's Syndrome. Based on the data provided by the Association for Autism and Developmental Disorders Monitoring (hereinafter referred to as ADDM), it was already established in 2015 that, on average, 1 in 68 children in the world was diagnosed with ASD. The disorder affects different racial, ethnic, and socioeconomic groups, but of all other ethnic groups, white people are more frequently affected. ASD are about 4.5 times more common in boys (1 in 42) than in girls (1 in 189). According to the statistical data provided by the Institute of Hygiene in 2020, the incidence of multiple developmental disorders in persons aged 0-17 increased up to 1.8 times in Lithuania from 2015 to 2019. In 2015, the incidence of multiple developmental disorders was 250/100,000 children, and in 2019, 452/100,000 children already. According to statistics, in 2015, there were 1308 children with multiple developmental disabilities, and the number increased to 2257 children in 2019.

In all analysed years, the rate of boys suffering from multiple developmental disorders was about 4 times higher than that of girls.

In Lithuania, disabled children and their families are provided with general and special social services. However, studies have determined that considering the needs, the spectrum of social services provided in some municipalities is insufficient. When implementing the rights of children with disabilities, the most important principle to be considered is Paragraph 1 of Article 23 of the United Nations Convention on the Rights of the Child, which states that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. The assistance and support should ensure that the family can freely and effectively use training, education, health, rehabilitation services and existing leisure opportunities.

**The subject of the research** is social support for families raising children with ASD.

**The article aims** to analyse social support for families raising children with ASD.

**The objectives are** to describe ASD, analyse the problems of parents raising a child with ASD, and determine the need for assistance for families raising a child with ASD.

**The research methods** include analysis of scientific literature, qualitative research, semi-structured interviews, and content analysis.

## Theoretical aspects of the autism spectrum

The World Health Organization (WHO) describes ASD as a person's persistent difficulties in the ability to initiate and maintain mutual social interaction and communication, repetitive, limited, unchanging interests that are atypical for the person's age and sociocultural context. This disorder usually manifests itself in early childhood. However, the symptoms of autism can also appear later when social norms exceed the individual's capabilities. Autism symptoms are severe enough and can impair a person's social relationships, academic performance, relationships, and other important life activities.

In the *Encyclopaedic Dictionary of Education*, Jovaisa (2007) describes ASD as a disorder that manifests itself in ignoring other people and pathological closure in one's own spiritual and emotional world. Such children are frightened by the changes in the environment; they do not communicate with other people due to impaired speech or lack of intelligence. Juchnevičiene et al. (2014) define ASD as one of the most complex developmental disorders. It is described as a pathological introversion of a person, which causes difficulty in communicating with, and emotional and social misunderstanding of, other persons. ASD symptoms are characterised by developmental abnormalities that cover a large part of mental functioning. It is typical for individuals with ASD to have lifelong problems of social interaction, communication, and behaviour. Sicile-Kira (2014) describes ASD as a disorder of the nervous system that affects the functioning of a person's brain and usually occurs during the first three years of a child's life. It is believed that men are four times more likely to be diagnosed with ASD than women.

Navickienė et al. (2019) state that ASD is a complex developmental disorder that determines individuals' qualitatively different and unique behaviour and perceptions. Children with ASD often experience isolation and negative evaluation of the people around them because they often lack social skills, have increased unproductive activity and impulsivity, often face learning difficulties, and lack motivation. According to the *International Classification of Diseases ICD-10* (2021), used throughout Europe and Lithuania, ASD disorders are classified as multifaceted (F 84). This group includes the following disorders: F84.0 Childhood Autism; F84.1 Atypical Autism; F84.2 Rett Syndrome; F84.3 other childhood disintegrative disorders; F84.4 Hyperactivity Disorder; and F84.5 Asperger's Syndrome.

Paediatricians (Hyman, Levy Myers, 2020) emphasise that in individuals with ASD, the main

abnormalities are usually found in two areas: social communication and interaction with other individuals and the behaviour that is atypical (restrictive, repetitive). Therefore, they need a lot of help in various areas, such as behavioural, educational, health, leisure, family support, etc.

Valionienė (2020) notes that the challenges faced by a person with ASD are not limited to the symptoms specific to this disorder. Often, together with ASD, other concurrent disorders are no less troublesome for the family of the impaired person and the professionals assisting.

Scientists (Geležinienė et al., 2011) emphasise that such children are characterised by stereotypic behaviour, strange speech expressions, and improper use of language. The inability to properly communicate with others causes many problems in communication, i.e., a child is unable to properly and timely express and convey his/her feelings, his/her language is more automated and inflexible, and he/she may often not understand the meaning of social and emotional communication. Also, such children do not understand or may misunderstand other people's mental state, the feelings expressed, jokes, proverbs, figurative phrases and words. They do not understand when another person is lying or is hypocritical.

The signs of ASD are very diverse. Grigėnaite (2020) distinguishes early signs of ASD, such as language expression and understanding, social skills and communication features, limited activities and interests, stereotypies, specific play, and sensory features.

There is no cure for ASD. However, various scientific studies show that it can be facilitated with various treatments. As Bolte (2014) points out, having ASD, the quality of life can be improved by applying educational measures, psychological therapies, and alternative therapies (massages, vitamins). Early intervention and early development of social skills alleviate ASD symptoms and improve the quality of a person's life. Mikulėnaite and Ulevičiūtė (2004) note that if ASD is not treated in childhood, many children do not acquire sufficient social skills necessary in their lives, and they may not learn to behave and speak appropriately. There are very few cases where this disorder is cured without any treatment. Currently, there are many different and effective ways to help people with ASD. However, the effect is different for each child. The same treatment can bring a great improvement to one child but have almost no effect on another child.

Studenka (2021) notes that today, parents are much more aware of the early symptoms of ASD because, recently, there has been a lot of information about this disorder in newspapers, on

television, and the Internet. Knowing the early symptoms, parents contact the child's doctor sooner and tell their observations; thus, the child and parents receive the necessary assistance.

ASD is a developmental disorder that disrupts a person's perception of the environment, language development, and social communication. Individuals with such a disorder often exhibit atypical behaviour (repetitive and restrictive). The disorder limits a person's ability to develop and function normally.

Environmental and genetic factors can influence the development of ASD. Today, there are many different effective ways of helping people with ASD that are adjusted to each individual's needs. If the necessary services and help are not provided in time, a person with ASD does not acquire the skills necessary to function as independently as possible. Appropriate assistance received in time allows a person to successfully improve, develop, integrate into society, and live a quality life.

Parents of a child with ASD can often feel helpless and lost in some situations. Burrell et al., (2017) observe that sometimes parents face problems in accepting their child's disability because of guilt, shame, and lack of knowledge on how to deal with their child's behaviour. As a result, it is difficult for parents to integrate into society and communicate with others, and they also experience stress, anxiety, and depression.

However, a survey conducted by Padden and James (2017) revealed that parents of children with such a disorder successfully try many different coping strategies, such as psychotherapy and self-help groups. Time planning, humour, acceptance of the disorder, religion, and sports help parents to cope with the current psychological state as well. Families may experience stigmatisation and isolation in society. When parents experience great anxiety, psychosomatic disorders may also occur. Trying to deal with anxiety, parents look for ways to help them overcome it. They visit mutual help groups and psychologist consultations, start planning time, use humour more, practice religion, and do sports.

In conclusion, it can be stated that a child's disability has a significant impact on the functions and roles of the entire family. Parents raising a child with ASD experience stress due to many factors, including a changed lifestyle as a disabled child requires more care, time and attention than a healthy child; financial expenses necessary for the education of a disabled child; and constant anxiety about the child's future. Parents also lack assistance from professionals.

Demanding legislation has been adopted to improve the lives of disabled persons, provide financial support, and integrate them into society in

Lithuania. It regulates various spheres, including financial support to disabled persons. If the need for care for a disabled person is determined, financial support is provided to the person who cares for him/her. There are also provisions for public transport allowances for the disabled person and his/her family; the possibility of adjusting housing and motor vehicles for people with disabilities; providing technical aids, health care, and education; and assisting the integration of disabled people into society.

Assistance to families and individuals related to ASD is provided. Non-governmental organisations such as "Lietaus vaikai" (*Children of the Rain*) and "Kitoks vaikas" (*Different Child*) organise targeted support for families, providing them with information and promoting awareness of ASD in society. They represent individuals who are diagnosed with ASD in various conferences, policy meetings, and projects and organise various training sessions important for the professionals working in various fields with individuals with ASD and families raising a child with this disorder.

Casey and Elswick (2011) describe social work with families raising children with ASD as long and highly professional social worker's activities with the family to help parents get financial and social support for their child's needs, providing counselling and information about social services, existing self-help groups, non-governmental organisations and financial and non-financial state support.

However, Bishop-Fitzpatrick et al. (2019) believe that social workers are neither theoretically nor practically prepared to encourage people to fully engage persons with ASD in public life and provide social and economic justice to these persons. A social worker who works with persons with ASD has to constantly update the available knowledge about ASD, methods of organising practical activities and education of these persons and providing support to the persons who have ASD and their families. Social work with families raising children with ASD is a long, professional job during which it is necessary to use a lot of practical and theoretical knowledge about the disorder and the ways to help people with ASD and their families. A social worker must have the skills and knowledge to perform the roles of contact worker, mediator, advocate, assessor, teacher, behaviour changer, mobiliser, consultant, community planner, service provider, data processor, coordinator, and enabler. It can be argued that these professional roles are not separable but intertwine in a specific case and fulfil certain professional roles.

## Research Methodology

A qualitative research method, a semi-structured interview, was used to collect empirical data. The research was conducted in September 2023, following the principles of research ethics.

8 mothers who raised children with ASD participated in the research: Viktorija, Agnė, Nijolė, Ana, Gabija, Marija, Laura, Augustė (names changed) (see Table 1).

**Table 1.** Socio-demographic data of the respondents

Name	Age	Education	Child's age	Child's disability level
Viktorija	25	Secondary	6	Severe
Agnė	48	Vocational	12	Severe
Nijolė	45	Vocational	17	Severe
Ana	37	Higher	10	Moderate
Gabija	34	Higher	4	Severe
Marija	50	Higher	17	Moderate
Laura	35	Higher	12	Severe
Augustė	39	Higher	10	Moderate

The parents who participated in the research are between 25 and 50 years old. 5 parents have higher education, 2 vocational, and 1 secondary. The families of the respondents are not large. Three families raise 1 child, four - 2, and only one family raises 3 children. Seven families have 1 child with ASD, and Ana's family has 2 girls (twins) with this disorder. Children with ASD are between 4 and 17 years old. The level of disability of 5 children is severe, 3 children have it moderate.

## Research findings and their discussion

The research revealed that the parents reacted differently to the child's diagnosis. Some parents fell into despair, others denied the child's disorder, but some accepted the child's diagnosis calmly. Different factors affected the nature of the reactions, i.e., *internal*, such as the child's age, distrust in medical personnel, being a single parent, knowledge of the disorder's symptoms, and *external*.

The research data have revealed that many factors influence the parents' denial of the child's diagnosis.

Viktorija stated that the age of her child greatly influenced her denial: "... after all, he is still very young, how can you decide so fast...". According to researchers Kavaliauskaitė and Kondratavičienė (2019), the reaction of denial is parents' common and very normal reaction upon learning of a child's diagnosis. Various factors, such as lack of communication with professionals, influence parents' poor state of health and despair.

Gabija stated that she fell into despair when, after the child's diagnosis, professionals stopped communicating with her: "...they gave me papers and said goodbye...".

According to Agnė, raising a child as a single mother is also a factor that made it difficult for her to accept the child's diagnosis: "... and I already raised him alone, and now I have to deal with the child's disability alone besides...".

The parents who participated in the study stated that the support of relatives, friends, and professionals greatly influenced their calm reaction to the diagnosis. After learning that a child has a disability, the whole family's life rhythm, habits, and functions change. The family has to adapt to the changed roles and new challenges. This situation can also change the relationship between the child's parents. Bawalsah (2016) notes that the stress caused by a child's disability can often change the relationship between parents. One of the parents often gives his/her full attention to their child, and the relationship between the parents often changes. The analysis of the research data allows claiming that the relationship between the parents changed after getting the child's diagnosis. However, other parents did not notice a change in their relationship. Three families stated that there were no changes in their relationship. In the families of Gabija and Laura, the relationship was described as improved. In the families of Viktorija and Augustė, the relationships worsened, and Agnė's family broke up.

The parents who participated in the research named their family's internal and external issues in raising a child with ASD (see Table 2).

**Table 2.** Internal and external issues

Category	Subcategory	Confirmatory statements
	Lack of independence	<...> he needs constant, uninterrupted care. He can never be left alone... (Viktorija)
Internal-issues		<...> it is difficult because we cannot leave him alone for long, even though he is already 12 years old... (Laura)
	Lack of finances	<...> I am raising the child alone; we are short of money to pay for disability and care... (Viktorija) <...> you have to spend a lot of money on therapy and occupation and save money... (Augustė)

Category	Subcategory	Confirmatory statements
	Leaving the child	<p>&lt;...&gt; when you need to go somewhere to see a doctor or somewhere, you have nowhere to leave him... (Agnè)</p> <p>&lt;...&gt; we have nowhere to leave the child when we have important things to do... (Nijolè)</p>
External issues	Work	<p>&lt;...&gt; it's hard to find a job because a disabled child gets sick more often, doctor visits are constant, sanatoriums, nobody wants to employ me... (Viktorija)</p> <p>&lt;...&gt; it is difficult with work; the first few workplaces did not accept me when they found out that I was raising a child with a disability who often gets sick... (Agnè)</p> <p>&lt;...&gt; I would like to return to work, but I also understand there are no possibilities for that... (Ana)</p> <p>&lt;...&gt; I still cannot find a job, even though I have higher education... (Gabija)</p>
	Bullying	<p>&lt;...&gt; I need to watch everyone, so they do not film him in public places and upload it to TikTok or YouTube because teenagers think it is funny... (Gabija)</p> <p>&lt;...&gt; bullying my son at school, they even created a bullying profile on social networks... (Marija)</p> <p>&lt;...&gt; other people's unkind glances at the child hurt a lot (Laura)</p>
	Lack of professionals	<p>&lt;...&gt; lack of specialists is a problem, we need normal assistance for our child... (Marija)</p>

To sum up, it can be stated that the problems faced by parents when raising a child with ASD are not always easy to solve. Some problems, such as bullying, employers' bias against parents of disabled children, and lack of necessary professionals in the town of residence can be difficult to solve because parents themselves cannot

influence it. The problems that parents cannot solve on their own or with the help of others cause stress and parents' various negative emotions. However, they state that it is necessary to solve problems independently.

Viktorija and Gabija named the independent overcoming of problems as working with oneself: *it is very important to work with yourself and tell yourself every day that everything will be fine. We both, my child and I are strong...* (Viktorija), *I read a book, and I encouraged myself and the whole family...* (Gabija). According to Nijolè and Gabija, relaxation can also solve problems because *... I get away from everything in nature, take a walk, reflect...* (Nijolè), *... I try to rest whenever possible because my thoughts come together, and it seems easier to live and look towards tomorrow* (Gabija). It can be concluded that thanks to personal effort and rest, parents can more easily deal with emerging problems, such as stress and poor emotional state.

However, not all problems can be solved by parents themselves; they need assistance from others. The parents who participated in the research mentioned that close people also helped them solve the problems. Viktorija was helped by her mother and sister in solving problems. She said that *it is easier to solve everything by being not alone*. Agnè, Laura, and Auguste received assistance in solving the problems from their grandmothers, grandfathers, and parents. Nijolè, Ana, and Marija identified the child's school staff, i.e., the child's class teachers and school psychologists, as one of the sources of assistance.

The research results suggest that working with oneself was identified by parents as one of the methods of independent problem-solving. Parents were very interested in all possible information and read and collected all possible information about what ASD is and how to deal with a child who has this disorder. Information and knowledge about the child's disability help them feel much stronger and safer in terms of coping with the child's emotions and developing the parenting process.

Parents received information about ASD, education and upbringing of such children from various sources. They named the Development Centre as a formal source of information. Four families stated that they received much information from the child's physician, while Marija and Augustè received information from the social worker. According to Gabija, she was given a leaflet containing information about her family's social support available from SODRA. The parents also named the Internet as an informal source of information. Two families received information from other families who also raised disabled children.

Social support is very necessary for families raising children with ASD. Harandi et al. (2017) describe social support for families raising disabled children as physical and psychological support for families facing physical or psychosocial difficulties. The authors note that providing high-quality social support to families with children with disabilities reduces their psychological experiences and makes it easier for them to cope with the current situation.

Based on the data obtained, it can be stated that all the parents who participated in the research received financial and social support from the state. They were allocated a child benefit disability pension and targeted compensation for the care of a disabled child. Along with financial support, parents also received social services.

Sanatorium treatment was offered to three families who learned about the child's diagnosis. Speech therapist services were provided to the children with ASD of Gabija, Augustè, and Laura. The children of three families also received a place in a special kindergarten. Ana was very happy with this opportunity because *many specialists worked with them in the kindergarten. Not only did I see the progress of the girls but also those around me.* Gabija stated that the psychologist helped not only her child but also her: *"both the child and I went to the psychologist; his various suggestions regarding parenting, distribution of responsibilities at home and listening helped me"*.

The social support available to families of children with ASD immediately after the child's diagnosis may not always be what the family needs. Arranging the necessary services/benefits/compensations is a long process, and families are not always aware of that because they need time and energy to deal with emotions, new challenges, and a changed rhythm of life.

Based on the data obtained, it can be said that the families used various forms of social support provided by the state. All families received child benefit disability pension and targeted compensation for caring for a disabled child. The families of Viktorija, Agnè, Gabija, and Augustè got the opportunity to take their children to the sanatorium every year. The families were happy with the sanatorium treatment and said *we would be at the sanatorium all summer if there was such an opportunity. They provide a lot of therapies and procedures that greatly contribute to the child's development...* (Augustè).

The families also receive children's education and occupation services. Gabija's and Viktorija's children attend a special kindergarten. Children from five families go to a special school, and Marija's child with ASD attends a general education school and is assigned a teacher's assistant who

helps the child not only learn but also orientate and gradually become more and more independent. The family also let their child attend a daycare centre.

Some families that participated in the research managed to get benefits and compensation. They purchased compensated technical equipment: *we got a tablet from the list, which helps us a lot with communication...* (Viktorija), *...a weighted blanket...* (Ana). Gabija mentioned that their family even managed to get several sensorimotor devices. The families also took advantage of transport discounts and compensations. Viktorija and Marija use public and intercity transport with a disabled person and an accompanying person's discount. Gabija's and Laura's families received car acquisition compensation. Gabija arranged for a car parking space for people with disabilities to be set near their apartment. The families of Gabija and Augustè also received dwelling adjustment compensation for disabled people.

A wide choice of social support is very important for families raising children with ASD because each child with such a disorder is very different, and each child may need different assistance. Therefore, each family may need different social support. Along with a wide choice of social support, its quality and meeting the needs of families are also very important. The families that participated in the research were familiar with and used quite a large part of the support offered by the state. However, families would like more help, especially occupation and therapies (Agnè), various specialists who, according to Agnè and Nijolé, have a very formal approach. Financial support is also insufficient.

To sum up, it can be stated that unsatisfied family social needs cause stress for the whole family. All parents who are satisfied with the provided social support and those who are not satisfied with it state that there will never be too much social support for the families raising children with ASD. A greater supply of services could help families feel safer. The most important things are financial support, free psychologist consultations, social worker assistance, various employment services, temporary respite care services, and more useful information about disorders.

After the child's diagnosis, families received various social support such as child's disability and care money, sanatorium treatment, speech therapist services, special kindergarten education services, and psychologist's services. As the children grew up, families began to receive more services: special school, daycare services, technical equipment, transportation benefits, dwelling adjustment compensations, and teacher's assistant support.

Parents had different opinions about the support received to meet the needs. The social support

received met the needs of some families but not all. Families stated that they lack financial support, free psychological consultations, access to information, social worker's assistance, child's occupation services, free therapies, temporary respite services, and qualified specialists.

## Conclusions

Scientific literature states that ASD is a complex developmental disorder that usually manifests in early childhood, during the first three years of a person's life, and can be influenced by genetic and biological factors. ASD includes childhood autism, atypical autism, Rett syndrome, Asperger's syndrome, and other multidimensional developmental disorders. The disorders cause persistent difficulties in various activities of the child's life: social relations, learning activities, acquisition of social skills, behaviour, and anger control.

## References

1. Bawalsah, J. A. (2016). Stress and Coping Strategies in Parents of Children with Physical, Mental, and Hearing Disabilities in Jordan. *International Journal of Education*, 8(1), 1-22. Doi: 10.5296/ije.v8i1.8811
2. Bishop-Fitzpatrick, L., Dababnah, S., Baker-Ericzen, M. J., Smith, M. J., Magana, S.M. (2019). Autism spectrum disorder and the science of social work: A grand challenge for social work research. *Social Work in Mental Health*, 17(1), 73-92. Doi: 10.1080/15332985.2018.1509411.
3. Bölte, S. (2014). Is autism curable? *Developmental Medicine & Child Neurology*, 56(10), 927-931. Doi: 10.1111/dmcn.12495
4. Burrell, A., Ives, J., Unwin, G. (2017). The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(4), 1135-1147. Doi: 10.1007/s10803-017-3035-2
5. Casey, L.B. & Elswick, S.E. (2011). The Social Worker's Role in the Assessment of Autism Spectrum Disorder. *Children & Schools*, 33(3), 176-183. Doi: 10.1093/cs/33.3.176
6. Darbo su neįgaliaisiais metodika. (2009). <http://esf.socmin.lt/katalogas/pdb/Produktai/VP1-1.3-SADM-02-K-01-092%20Darbo%20su%20neįgaliaisiais%20metodika.pdf>
7. Dėl Būsto pritaikymo neįgaliesiems tvarkos aprašo patvirtinimo, Nr:A1-103. (2019). <https://eseimas.lrs.lt/portal/legalAct/lt/TAD/b0f12721361811e98893d5af47354b00/asr>
8. Dėl neįgaliųjų aprūpinimo techninės pagalbos priemonėmis ir šių priemonių įsigijimo išlaidų kompensavimo tvarkos aprašo patvirtinimo, No. A1-338. (2006). <https://eseimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.289658/FCAjkhkmZo>
9. Geležinienė, R., Vasiliauskienė, L., Vyšniauskienė, A. (2011). *Mokomės kartu*. Specialiosios pedagogikos ir psichologijos centras.
10. Grigėnaitė, J. (2020). Ankstyvojo amžiaus autizmo spektro sutrikimų turinčių vaikų funkcinio elgesio vertinimas bendradarbiaujant šeimoms ir logopedui. *Specialusis ugdymas*, 1(41), 103-138. Doi: 10.21277/se.v1i41.527
11. Hyman, S.L., Levy, S.E., Myers, S.M. (2020). Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics*, 145(1). Doi:10.1542/peds.2019-3447
12. Juchnevičienė, R., Mačiulienė, D. Juškytė, V. (2014). Tėvų, auginančių vaikus, turinčius autizmo sindromą, nuomonė apie dantų ėduonies profilaktikos galimybes. *Sveikatos mokslai*, 24(6), 1-5. Doi:10.5200/sm-hs.2014.109
13. Kavaliauskienė, A., Kondratavičienė, V. (2019). *Formalios ir neformalios socialinės pagalbos šeimoms ypatumai. Praktiniai patarimai tėveliams, auginantiems negalią turintį vaiką*. Kaunas: Vitae Litera.
14. Mikulėnaitė, L., Ulevičiūtė R. (2004). *Ankstyvojo amžiaus vaikų autizmas*. Vilnius.
15. Navickienė, L., Piščalkienė, V., Mikulėnaitė, L., Grikainienė, L., Tender, J., Bukauskaitė, M., Sulinskas, U., Sate, G. (2019). *Kaip padėti vaikui, turinčiam autizmo spektro sutrikimą*. Vilnius: Lietuvos Respublikos švietimo, mokslo ir sporto ministerija.
16. Sicile-Kara, C. (2014). *Autism Spectrum Disorder (revised): The Complete Guide to Understanding Autism*. JAV.
17. Tarptautinis ligų klasifikatorius. F84. Įvairiapusiai raidos sutrikimai. <http://ebook.vlk.lt/e.vadovas/index.jsp?topic=/lt.webme dia.vlk.drg.icd.ebook.content/html/icd/ivadas.html>
18. Valionienė, L. (2019). *Autizmas ir gretutiniai sutrikimai*. Lietaus vaikai. 4. 6-8. <http://online.fliphtml5.com/cvlgb/shza/#p=2>

## SOCIALINĖ PARAMA ŠEIMOMS, AUGINANČIOMS VAIKUS, TURINČIUS AUTIZMO SPEKTRO SUTRIKIMUS

### Santrauka

Straipsnyje apžvelgiamos šeimų, auginančių vaikus, turinčius autizmo spektro sutrikimus, problemos bei pagalbos galimybės. Tikslas – išanalizuoti socialinę paramą šeimoms, auginančioms vaikus, turinčius autizmo spektro sutrikimą. Uždaviniai: aprašyti autizmo spektro sutrikimą; ištirti tėvų, auginančių vaiką, turintį autizmo spektro sutrikimą, problemas; nustatyti pagalbos poreikį šeimoms, auginančioms vaiką, turintį autizmo spektro sutrikimą. Teorinėje dalyje aptariama autizmo spektro sutrikimo samprata, apžvelgiami teisės aktai, reglamentuojantys paramą šeimai bei socialinio darbuotojo pagalbos poreikis šioms šeimoms. Tyrimas atskleidė, kad augindami autizmo spektro sutrikimą turintį vaiką tėvai dažnai susiduria su tokiomis problemomis kaip finansiniai sunkumai, sutrikęs gyvenimo ritmas, pasikeitusios šeimos funkcijos, santykių pasikeitimas šeimoje, patiriamas stresas ir nerimas. Tėvai dažnai negali susirasti darbo, nes darbdaviai nesudaro tokių sąlygų, kad tėvų darbo laikas būtų priderintas prie vaiko ugdymo įstaigos darbo laiko. Tėvai, auginantys vaikus, turinčius autizmo spektro sutrikimą, susiduria su visuomenės atstūmimu ir patyčiomis bei kvalifikuotų specialistų ir reikalingos socialinės paramos trūkumu. Nustatyta, kad šeimoms, auginančioms vaikus, turinčius autizmo spektro sutrikimą, trūksta nemokamų psichologo konsultacijų, didesnės finansinės paramos, informacijos apie autizmo spektro sutrikimą ir socialinės paramos galimybes vienoje vietoje, socialinio darbuotojo paslaugų, užimtumo paslaugų vaikams, nemokamų terapijų pasirinkimo galimybių, laikino atokvėpio paslaugos ir kvalifikuotų specialistų, paruoštų dirbti su vaikais, turinčiais autizmo spektro sutrikimą.

**Reikšminiai žodžiai:** autizmo spektro sutrikimas, vaikystės autizmas, netipiškas autizmas, Aspergerio sindromas, pasekmės

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