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SOCIAL SERVICES TO HELP ACHIEVE A BALANCED LIFE FOR FAMILIES WITH DISABLED CHILDREN: A CASE STUDY

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Abstract

Purpose. The aim of this study is to reveal the peculiarities of the provision of social services for families with disabled children and the need for these services by examining the experience of clients in Druskininkai municipality.

Design/methodology/approach. To achieve the goal of the study, a quantitative study based on a normative strategy was chosen. The method of quantitative research was chosen because of its characteristic forms, the desire to search for external features, to measure and calculate them, to seek a single explanation, laws, rules, universality and universality. Quantitative research seeks to develop and validate common theories of human behavior that view grouping as reality and are independent of the individual.

Findings. In Lithuania, families balance on the verge of socio-economic survival. Basic needs are becoming an important indicator of family life, so it would be too difficult to talk about the need for a balanced life. Emotional and psychological support for families is provided in a fragmented way, usually within the framework of time-limited project activities. As noted, there is a need to improve the provision of social services in municipalities, taking into account the individual needs of parents, strengthening the emotional resilience of the family, helping the family to adapt to the new reality. It is necessary to create a systematic support mechanism for the family, which would help to coordinate the provision of services in implementing the importance of a balanced life in the family.

Research limitations/implications. The survey uses a questionnaire to meet the respondent directly or to send a questionnaire by e-mail. The study provided an opportunity to ask additional clarifying questions, and when the subject did not understand the question, it was possible to ask the question in a form that was more understandable to him. In order not only to listen, but also to encourage the research participant to express their thoughts, share experiences and views on the phenomenon under study, a interview with the respondent was chosen by filling in the questionnaire.

Practical implications. The results of this study may be useful for the government, municipalities in making management decisions that would help to achieve a balanced life support mechanism for families raising children with disabilities.

Originality/Value. Compared to 2019; 2020 and 2021 research results, the author of the article identified the importance of the need for help for families raising children with disabilities. The study identified the needs of social services that help to achieve a balanced life for families raising children with disabilities.

Keywords: disability, family, social services, life balanced.

Research type: research paper.

JEL classification: L2, Y9, I38, H1.

Introduction

The prevailing model of comprehensive family support in Lithuania includes three main areas of health, education and social. Institutions focus on seeking help for a child with a disability in education, analyse issues of access to services, but do not delve into the importance of a balanced life for a family raising a disabled child. The focus is on individual segments, but not on the whole, in other words, on complex support that would help the family to function successfully in socio-economic areas. Finally, the resulting psychological-emotional imbalance in the family may be due to a lack of focus on healthy living. Educating the family, training on healthy lifestyles, informing about the possibilities of help deepens the knowledge about ways to preserve and strengthen health. The need for social services assistance has increased in Lithuanian municipalities and new forms of social services are being developed in order to achieve more optimal and efficient management.

Taking into account the discussed need for balanced life social services, the problems of families raising children with disabilities and the relevance of the study, the following research question is raised: what is the need for balanced life social services for families raising children with disabilities? The need for balanced lifestyle social services for families with disabled children in Druskininkai municipality will be analysed.

The aim of this study is to reveal the peculiarities of the provision of social services for families with disabled children and the need for these services by examining the experience of clients in Druskininkai municipality. The research was carried out in the territory of Druskininkai municipality. Research internship was carried out in the Social Support Division of the Druskininkai Municipality Administration, a tripartite agreement was signed guaranteeing confidentiality and ensuring data security. During the internship, contact data were collected from individuals who are raising children with disabilities.

The article consists of three main parts: theoretical analysis of the need for balanced lifestyle social services, presentation of empirical research methodology and analysis of the results of the research. A final consideration of the research is formulated at the end of the article.

1. Theoretical background

Recently, in Lithuania, more and more attention is paid to families raising children with disabilities. This is significantly related to the adopted laws and other documents that emphasize the role of the family in the process of full development and integration of a child with a disability into society. According to the data of the Ministry of Social Security and Labour of the Republic of Lithuania, the number of children with disabilities in 2019, as compared to 2018, increased and reached 15.3 thousand (Ministry of Social Security and Labour of the Republic of Lithuania, 2021).

From a theoretical and legal point of view, it is declared that families raising children with disabilities can receive assistance at the state and municipal level and thus function successfully in all areas of life. One of the main functions of social security is the provision of social services to the population, which is identified as a product of modern society and arose from the belief that the state, as a social system, is capable of solving social problems. On the other hand, in the modern state social support in material terms is becoming an alternative to social services. Providing targeted, individualized social services to the family can be a great support and incentive in their lives. In Lithuanian municipalities, services are provided in a fragmented manner, often influenced by administered financial resources. Studies have been performed on measures to help a disabled child in the fields of education, social life and health, but the full functioning of the family in society and economic - social, healthy lifestyle, quality of life indicators are not widely analysed.

One of the most important indicators of each country, regardless of its level of development, is the social stability of the society, and increasing social inclusion is the most important goal of the social economy (Ramaškienė and Šumskienė, 2020). Non-participation in the labour market, social isolation and lack of comprehensive assistance directly affect the emotional and psychological state of family health. Similar trends and issues prevail in other countries. Depending on the level of economic and social development of the country and the prevailing values, assistance is organized for a family with a disabled child. The experiences of the countries show that families raising a child with a disability focus on the child's care, education, health promotion and forget about their personal needs as parents. Parental emotional and psychological health directly affects family adaptation processes and involvement in community life. It should be noted that parents raising children with disabilities more often emphasize the lack of help, but not the need for a quality balanced life. Parents often neglect their health needs due to lack of time, fatigue, worries, forget to take care of their health or simply do not have the opportunity to do so. It is assumed that the psychological and emotional imbalance of the family is caused by too little attention paid to a healthy lifestyle. As a result, preventive health programs and educational programs on healthy lifestyle are considered necessary.

A healthy lifestyle is an integral part of human behaviour that reduces the chance of getting sick (Finger et al., 2019). Rapolienė et al. (2017) state that healthy lifestyle is a multidimensional concept that includes various components: diet, physical activity, non-use of tobacco, non-use of pharmaceuticals, non-use of alcohol and other psychoactive substances, work and rest regime, sexual behaviour, stress and the ability to cope with it, hygiene habits, preventive health screening and other behaviours that may affect health. The health care system should focus on improving the quality of family life (Perrin et al., 2020). One of the most effective ways to improve the physical and emotional health of parents and other family members, helping to reduce fatigue and stress is

counselling and psychosocial support (Piščalkienė and Navickienė, 2019). It should be assumed that the health problems of parents raising children with disabilities are exacerbated by the lack of services, non-participation in the labour market and social exclusion.

U.S. researchers studying parents' experiences after the birth of a child with a disability say that for some parents, the birth of a child with a disability was the beginning of a healthy lifestyle. The researcher distinguishes two tendencies, firstly the parents abandoned themselves and cared only for the child's well-being, secondly the parents changed their lifestyle towards a healthy lifestyle, they were forced to experience difficult existential life periods that they would not have experienced without a disabled child (Rigles, 2019).

It is important to note that disability is identified as a stigma in scientific publications. Rigles (2019) believes that stigma associated with disability is an additional stress that can negatively affect the health behaviours of family members. Other authors take the view that disability is a stigma as a certain trait that distinguishes a person's ability to engage in daily activities and feel a full participant in society. In addition, people with disabilities are rarely accepted in society as equal and full members. Disability covers a wide range of physical and mental disorders, thus limiting human activities and opportunities to participate in community life. The United Nations Convention on the Rights of Persons with Disabilities emphasizes that persons with disabilities have the same freedoms and rights as all other persons. It is obvious that the problem is based on socio-political arguments that disability stems primarily from a social environment that is not adapted to the needs of people with disabilities and from the inability of people with disabilities to adapt to the environment. It is believed that the lack of tolerance for various socially sensitive groups in society in Lithuania shows the importance of public education (Ramaškienė and Šumskienė, 2020). Versatile assistance is needed to create a comprehensive assistance system (Brighton and Townsend, 2021).

Disability covers a wide range of physical and mental disorders, thus limiting human activity and the ability to participate in community life (Rigles, 2019). It is obvious that in this case the social interaction of the family changes and its members have to deal with various life challenges. There is a noticeable trend where it is becoming increasingly difficult for parents to reconcile work and family life and to allocate time and energy resources properly (McConnell et al., 2012). According to Lynch (2000), income inequality affects health as a person perceives his or her place in the social hierarchy according to income. This perception generates negative emotions that have a direct impact on human health. Families raising children with disabilities can also experience this condition. Research has shown that employment relationships directly affect family's emotional well-being (Stefanidis and Strogilos, 2020). U.S. researchers note that parents raising children with disabilities describe their life experiences as a balancing mechanism in which they constantly seek

to maintain a balance between child support processes and emotional support for themselves (Singh et al., 2018).

Support for families is important not only in the fragmented stages of life; it also needs to ensure its continuity (McConnell et al., 2015). The scientific discourse actualizes the concept of a disability situation, in which from the disabled person as the centre of the problem, all persons related to him are noticeable and accessible. Due to the child's disability, the family experiences psychological stress, social exclusion, moral and value transformations, significant breaks (Vaičekauskaitė, 2008). Baumgardner (2019) investigated the factors that determine the social isolation of a family. It turned out that children with disabilities growing up in the family also experience difficult psychological and emotional experiences. Siblings may try to avoid public family outings for fear of inconvenience due to the physical appearance of the disabled sibling, unpredictable behavior, or the reaction of the people around them. McConkey et al. (2021), notes that the level of well-being of families that engage in community activities is significantly better than that of socially excluded families.

Research has shown that home help, educational programs for parents, respite services have helped to overcome the challenges of a child's disability, accept a child's disability and simply "learn to live" with a changed life situation (McConnell and Savage 2015). The benefits of the intervention program are also discussed by Rook et al. (2019). Gorica (2020) believes that it is expedient to organize trainings for parents with comprehensive content, to create methodological-informative publications containing the rights of families with disabilities, possible service packages. Informal sources of support also help to strengthen social relations in the family (McConnell et al., 2012). Active Israeli communities organize family weekends and / or camps only for a child with a disability, which provides respite for the whole family. There is a support group "special needs family" in the local community, "brothers and sisters days" are organized. These are support groups that give families the opportunity to come together and share experiences (Baumgardner, 2019). As parents develop new skills, participate in social and community activities, emotional resilience strengthens, relations with the child with a disability improve (McConkey et al., 2021).

Analysing the importance of a balanced life in families with a child with a disability, it is observed that the child's activity participating in sports and artistic activities respond to the relations of the whole family (Williams et al., 2020). Firstly, if the child participates in the educational process, extracurricular activities, attends a day centre, parents have the opportunity to relax or participate in the labour market. Secondly, parents experience less stress due to stigmatization processes; they develop social relationships and reduce the risk of social isolation, thus improving emotional-psychological well-being. It has been established that children with disabilities

participating in sports and artistic activities have increased self-esteem and self-confidence indicators. There is a link between the result and the establishment of a relationship with the coach in sports activities (Allan et al., 2019). For children with disabilities, contact with the person running the activities is particularly important. Human capital influences a child's motivation, performance, and involvement in activities. Family well-being depends on systematic and personalized support (McConkey et al., 2021). It is obvious that the situation of parents raising children with disabilities in different countries is complicated, complex and dependent on the assistance mechanism existing in that country.

In some countries, individual home help for a family raising children with disabilities has paid off. In Lithuania, home services for families raising children with disabilities are not widely practiced, Statistics show that the majority (80.7%) of persons who have received social services at home are of retirement age, 18% are people of working age with disabilities, and only 1.3% are children with disabilities (Lithuanian Department of Statistics, 2021). Before providing social services at home to a family raising a disabled child, as required by law, the person's need for social services and social care and the level of independence must be assessed. According to the Law on Social Services (2006), for families raising children with disabilities, social care must be classified as social services at home, which are divided into daily, short-term and long-term. A family receiving these services could leave their disabled child in the care of qualified professionals. It is obvious that this service is almost not provided in Lithuania. On the other hand, some parents, after long-term care for children with disabilities, refuse respite service due to distrust of strangers, unwillingness to let a stranger into their home (Baumgardner, 2019).

It is noted that there are also systemic problems in Lithuania when there is a lack of a unified information system on the level of disability established for children. Thus, until a family raising a disabled child applies for social services, municipalities do not have the opportunity to determine the need for social services, which means they cannot plan funding for the provision of social services. It is important to note that in 2019 Lithuanian municipalities did not use the 11.9 million euros allocated to the social field (https://socmin.lrv.lt). Taking it into account, it is assumed that if there is no need from a family raising a child with a disability, the municipality has no goal of organizing the provision of services.

There are more and more parents in Lithuania who share success stories, initiate the establishment of associations such as „Kitoks vaikas", „Saulytės", which unite parents and accept a child with a disability as a gift that allowed them to look at life from a different perspective. These organizations develop parental competencies on how to "learn to live" with a child with a disability and inform parents about help options.

In Lithuania, even the basic needs of a family raising a child with special needs are not met. Both parents and the administration focus on helping the child, but not on the parents' psychological and emotional health care. Taking into account the discussed aspects of the need for family social services, the topic of balanced lifestyle is not widely analysed in Lithuania. Parents experience imbalances due to constant tension, uncertainty, and physical and emotional fatigue. A frequent consequence of imbalances is intensifying processes of change (Grigužauskaitė and Skučienė, 2019). Thus, parents raising disabled children balance between the limits of economic - social survival, meeting their own and the child's needs and psychological - emotional exhaustion.

2. Research methodology

The aim of the research is to reveal the peculiarities and practice of providing social services to families with disabled children by examining the experience of clients in Druskininkai municipality. Sampling criteria are parents raising children with disabilities and living in Druskininkai municipality. In the study, the provision of social services to families raising children with disabilities was examined on the basis of a holistic approach. During the research, there were 83 families raising children with disabilities living in Druskininkai municipality. The selective sample of the research coincides with the general sample. Sixty-eight parents representing 68 families raising a disabled child from birth to 18 years of age participated in the research.

The analysis of scientific literature was first used for the research. Based on the existing theories and scientific research, an approach to the researched phenomenon is formed and the main direction of the research is determined (Kardelis, 2016). The research was conducted on the basis of ecological theory of systems. The application of ecological theory of systems in the context of the provision of social services takes into account the parts of the system, the interaction of parts, the relationships of individual parts, the whole, the relationships of the environment and the ways of communication.

According to the ecological theory of systems, the most important is the harmony of the interaction between man and the social environment. By the interaction of these components, personality change can be achieved, thereby facilitating integration processes, changing the impact of the environment, and meeting human needs.

To achieve the goal of the research, a quantitative study based on a normative strategy was chosen. The method of quantitative research was chosen due to its characteristic forms, the pursuit of search for external features, to measure and calculate them, to seek a single explanation, laws, rules, versatility and universality (Kardelis, 2016).

The aim of the research is to reveal the peculiarities of the provision of social services for families with disabled children, the frequency of use and the need for services, examining the experience of clients in Druskininkai municipality.

A standardized questionnaire is used to conduct a survey of families raising children with disabilities in Druskininkai municipality. A questionnaire is a set of questions formulated in a certain way, with a standardized procedure for filling in the questionnaire, which is based on the questions and formulated response options (Gaižauskaitė and Mikėnė, 2014). Questionnaires for families with a child with a disability were used for data collection. The structure of the questionnaire consists of 19 questions; it is clear, simple and understandable to the respondent. Prior to answering the questions, respondents had access to essential information about the study, which was provided in the introduction to the questionnaire as an integral part. The questions formed at the beginning of the questionnaire are quite easy, clearly understandable, and attract the attention of the respondent. The middle of the questionnaire focuses on the more difficult, essential questions of the topic, and at the end, easier and faster answered questions are presented again. (Gaižauskaitė and Mikėnė, 2014).

The questionnaire uses interval, rank, nominal and relative scales. When compiling the questionnaire, the respondents were asked to assess their satisfaction with the provided social services in Druskininkai municipality. A scale of 1-10 statements is chosen. The Likert scale is used for the question of which social services are needed in Druskininkai municipality. Respondents are asked to rate each statement in terms of necessity or redundancy (e.g., very necessary, partially required, I am not sure, partially redundant, completely redundant). Likert scales are widely used in attitude research.

The research was carried out in the territory of Druskininkai municipality. Research time: July – September, 2017. Four families lacking social skills and experiencing social risk were among the respondents. Social workers working with families at social risk were used to help interviewing these families. Ethical principles were maintained at all stages of the research and the wishes of the respondent were taken into account.

Depending on the ethics of the research, all the participants were interviewed individually. Ethical principles were followed during the research. All participants of the research were informed about the purpose of the study, the use and protection of data, ensuring confidentiality and adherence to ethical principles.

The anonymity of participants and research data was preserved during the research. The point is that the information provided by the research participants, despite its openness and personalism, does not allow the identification of the respondents. Anonymity was guaranteed by a questionnaire without names and meeting details.

3. Research results and findings

The data collected during the research were processed by the computer program SPSS. Mean, standard deviation, and median were calculated. 68 families participated in the research, 5 of them refused to participate in the survey, and 10 of them did not provide an answer.

The historically inherited centralized stationary social care system for the disabled existing in Lithuania creates unfavourable conditions for municipalities to develop social services that would provide day employment, accommodation, temporary family respite and personal assistance for the disabled. With this in mind, study participants were asked to indicate what social services they lacked. The distribution of the answers of the study participants is presented in Figure 1.

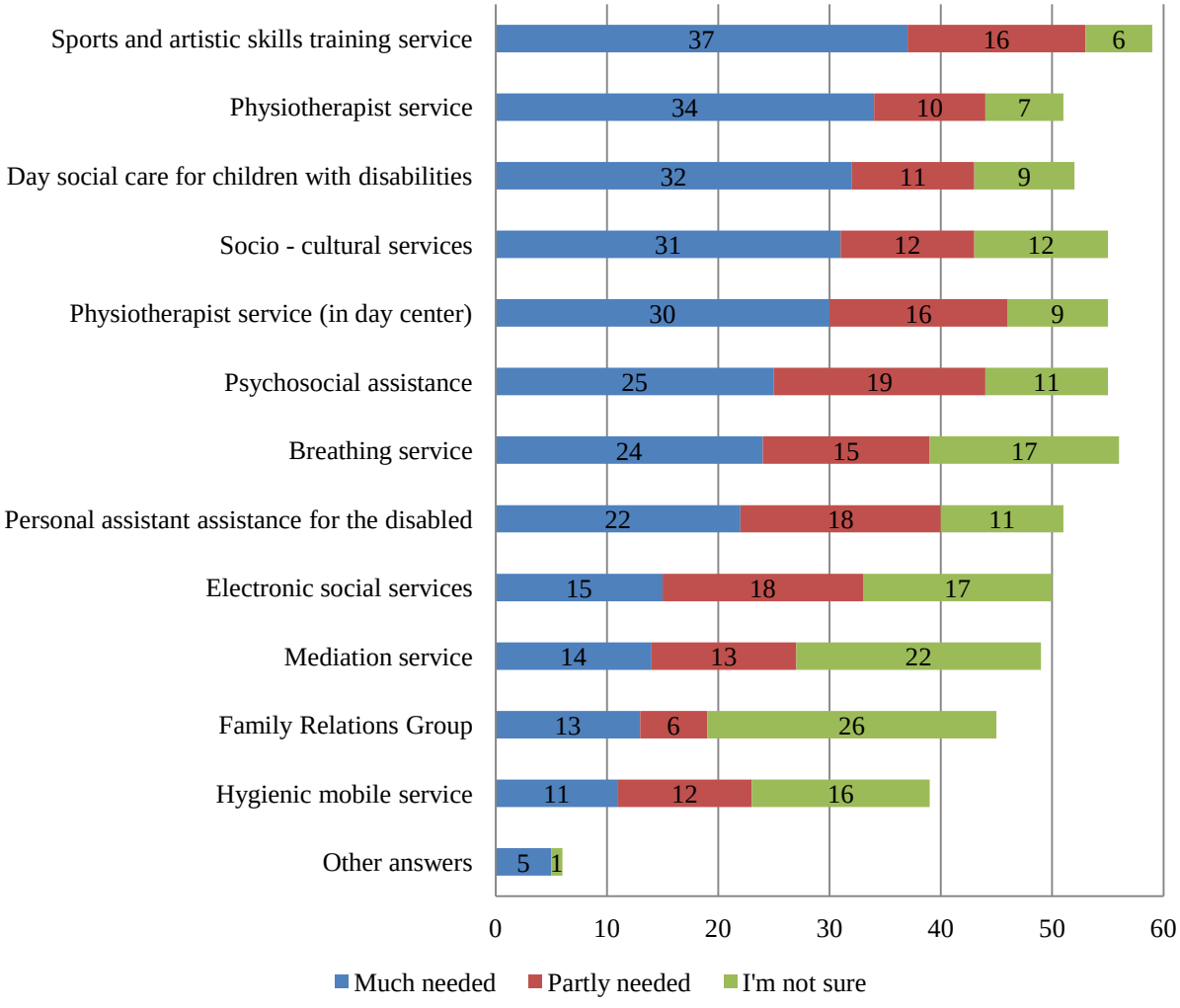


Figure 1. Distribution of respondents' answers according to the expressed need for services (in absolute numbers, N=68)

As the data presented in Figure 1 show, respondents are most in favour of sports and artistic skills development services, 37 parents who participated in the survey indicated that they really need this service, 16 - partially needed, 6 - not sure about this service, 1 - partially unnecessary and 8 respondents indicated that they do not need this service at all. More than half of the surveyed

parents (N = 46) indicated that their children need the services of a physiotherapist. According to the answers provided, the family relationship group service (N = 19) and the hygiene mobile service (N=23) are the least needed. Among the answers was the option “other”, which was chosen by 5 respondents who answered that their disabled child was missing “spec. pedagogue at school ”,“ specialists working with ABA methods ”,“ qualified spec. educators and assistants ”,“ respite services (at home) ”,“ teaching methods for autistic people ”,“ extend the working hours of DC “Hope” to 5 p.m. ” etc. On the other hand, research in the United States has found that professional counselling, formal and informal support groups, and parent self-help groups set up on online platforms have helped parents raising children with disabilities to overcome stress and isolation. (Reshmi et al. 2018). Parents clearly lack respite services, which may correlate with little-expressed need for a family relationship group. It is assumed that parents focus on caring for the child, forgetting to nurture emotional and psychological well-being in the family.

Analysing the links between the need for a sports and artistic skills training service and the place of residence of the respondents (see Figure 2); it was observed that the greatest need was expressed by families living in the city. According to the need for sports and artistic skills training service, the characteristics of the values are: mean - 1.93, standard deviation - 1.331, median - 1.00. It is clear that parents raising children with disabilities seek the same activities and child welfare as families raising a child of typical development. (Reshmi et al., 2018).

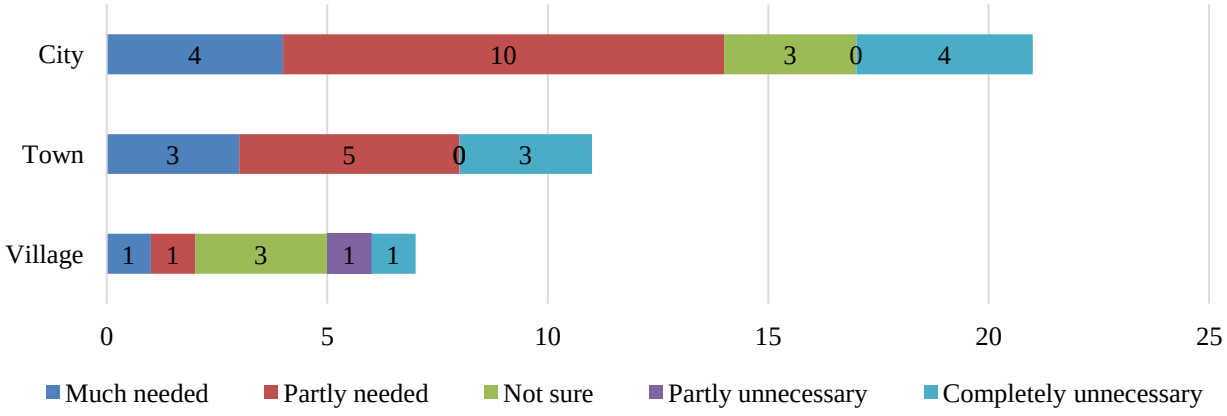


Figure 2. Need for sports and artistic skills development service by place of residence (in absolute numbers, N = 68)

An analysis of the links between the aforementioned service and the level of disability of the child was also made. The highest need (N = 26) was found for families with a child with a moderate level of disability. This may be due to the low supply of social services and activities for children with special needs (See Figure 3).

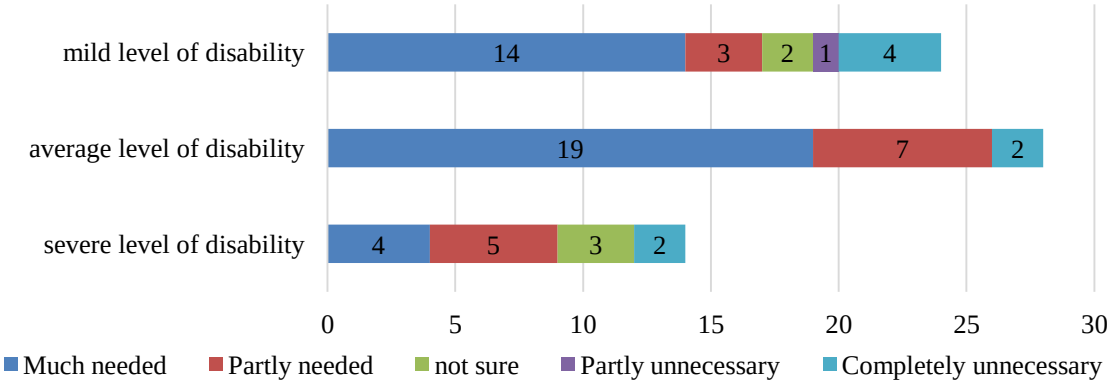


Figure 3. Need for sports and artistic skills development service according to the level of the child's disability (in absolute numbers, N = 68)

The need for socio-cultural services was expressed by 43 respondents. Comparing the links between the need for these services and the age of the child, it can be seen that the greatest need was expressed by families with children aged 7 to 12 (N = 19), families with children aged 13 to 18 (N = 11), 4 to 6 years (N = 8) and five respondents expressed a desire for these services for children aged 0 to 3 years. (See Figure 4)

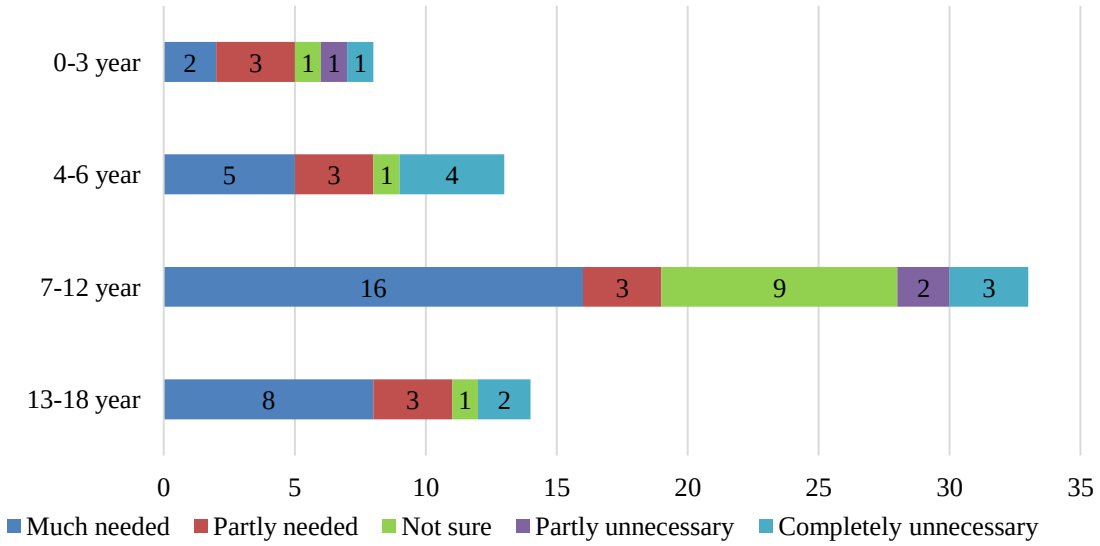


Figure 4. Need for socio - cultural services by child's age (in absolute numbers, N = 68)

It is difficult for family members raising and caring for a disabled person to reconcile family life with work. Families with children with disabilities were asked to indicate how many of them participate in the labour market. 35 respondents indicated that both parents work, 16 - only mother works, 12 - only father works, 3 - both parents do not work, 1 - did not answer, 1 respondent chose the answer "other" and entered the answer variant: "single mother", "single mother - not working ". This distribution of results lets assume that in Druskininkai municipality, families raising children with disabilities manage to combine work and child nursing and care. (See Figure 5) Compared to

the analyses of other countries, proportionally half of the parents or one of them is not working; the reason is the need for constant care for a child with a disability. Of course, this directly affects the social-emotional life of parents and family budget income (Gorica, 2020).

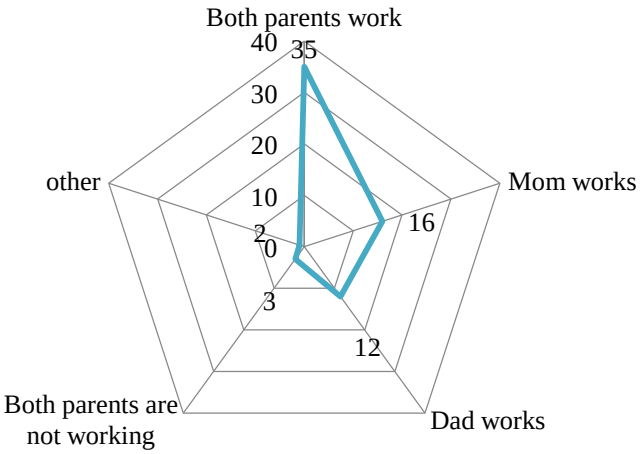


Figure 5. Distribution of respondents' answers by participation in the labour market (in absolute numbers, N = 68)

The study found that families raising children with disabilities still lack information about social services in Druskininkai municipality. It is assumed that this results in a low percentage of use of social services for families raising children with special needs.

1 table. Sources of information on social services (in absolute numbers, N = 68)

SOURCES OF INFORMATION ON SOCIAL SERVICES	TOTAL
Little information on social services	28
Child Rights Protection Division of Druskininkai Municipality Administration	1
Druskininkai municipality website www.druskininkai.lt	8
Druskininkai Municipality Social Services Center	8
Druskininkai Municipality Administration Social Support Division	14
Medical staff	19
Neighbours, friends	21

Table 1 shows that families raising disabled children usually receive information about social services from neighbours and friends (N = 21), the second most popular source of information is medical staff (N = 19). Respondents also noted that the information was provided to them by the Social Support Division of Druskininkai Municipality Administration (N = 15), Druskininkai Municipality Social Services Centre (N = 8), Druskininkai Municipality Administration Child Rights Protection Division (N = 1), and indicated as the source of information (N = 7) Druskininkai municipality website www.druskininkai.lt. Respondents who could not find a suitable answer option could enter their option. This was done by 5 respondents, who indicated that they receive

information from the “pedagogical psychological service”, “press”, “social networks” and “school social workers”. The role of the Social Support Division, the Centre for Social Services, in providing information about social services is also important. As many as 28 respondents believe that there is little information about the social services provided. This suggests that there are few families using social services due to a lack of information.

4. Conclusions

The majority of respondents expressed the need for services of sports and artistic skills development. There is a clear need to ensure the participation of children with disabilities in educational activities, summer recreation programs and sports and artistic skills programs. The result of the research allows to state that parents raising children with disabilities seek the same activities for their child as parents raising children with typical development. It turned out that the greatest need for sports and artistic services was expressed by families living in the city. It is obvious that family social inclusion, participation in community activities and ultimately emotional well-being depend on the family's living environment. It should be assumed that families living in urban areas experience less social isolation than parents living in rural areas.

Our study found that parents lack services that meet their child's individual needs, that the needs of children with special educational needs are not taken into account enough, and that there is a lack of a speech therapist, psychologist, special educator or other necessary specialists.

Family members raising and caring for a disabled person find it difficult to reconcile family life with work. The results of the survey have shown that more than half of the surveyed parents participate in labour market processes in Druskininkai municipality.

Our study found that families raising a child with a disability lack information about social services. The family's ability to take care of health, change their lifestyle and behaviour, and use the services offered by the state depends on the parents' awareness. Counselling and information are important factors in maintaining a family and avoiding the social isolation of parents. Taking into account the expressed need, it is recommended to organize parental education, to inform about the possible forms of services, the existing sources of help, and the added value they create.

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