

PECULIARITIES AND PRACTICE OF SOCIAL SERVICES FOR FAMILIES WITH DISABLED CHILDREN IN LITHUANIA

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Abstract

The article reveals the problems of providing social services to families with children with disabilities, the peculiarities of individual and comprehensive assistance and practice, based on the experience of foreign countries. In Lithuania, the possibilities of support measures for families raising children with disabilities are relevant and analyzed in the scientific discourse. Nevertheless, it is noticeable that individual segments are analyzed, such as the needs of the child with a disability, his education, inclusion, leaving the concepts of parents' quality of life. Good practice in foreign countries shows that targeted and systematic management of services can ensure the provision of individual assistance to children with disabilities and their parents, as a result of which the emotional well-being of the whole family improves. Institutions responsible for the provision of services to the family in Lithuania seek to discover a complex assistance mechanism that would ensure the successful functioning of families raising disabled children in public life. This requires a systematic process of inter-institutional cooperation that brings together individual segments and ensures access to help for families with children with disabilities. The research methodology was chosen by a systematic comparative analysis of the scientific literature, which revealed the peculiarities and practice of the provision of social services in Lithuania and foreign countries. The main factors that are identified as support for the family and the child with a disability are analyzed. The study aims to highlight which social services would improve the quality of life of a family with a child with a disability in response to the needs of the child and parents.

Purpose – the aim of this article is to reveal the peculiarities of the provision of social services for families with disabled children and the need for services in Lithuania, based on theoretical analysis.

Design/methodology/approach – peculiarities of social services provision and practice in Lithuania are analyzed, systematic and logical analysis of scientific literature is performed.

Finding – the analysis of the scientific literature allowed to identify the main features and practices of social service provision.

Research limitations/implications – the limitation of the study is that too little attention is paid to the features of social service provision that the literature describes as important for families raising children with disabilities.

Practical implications – the results of this study can be useful for the government, municipalities in making decisions that would help to create a systematic mechanism for the provision of social services to families raising children with disabilities.

Originality/Value – based on the results of the analysis of scientific literature sources, the author of the article identified the main features of the provision of social services and assistance opportunities for families raising children with disabilities.

Keywords: disability, family, social services.

Research type: literature review.

Introduction

The organization of social services for families raising disabled children is becoming an increasingly important issue in the context of Lithuanian social policy-making. Although in 2010 Lithuania has ratified the United Nations Convention on the Rights of Persons with Disabilities, which also commits to ensuring the roles of families raising children with disabilities in the processes of full development and integration into society. However, research shows that every family raising a disabled child faces many problems that require the provision of comprehensive care. First, they are overwhelmed by the diagnosis. When a disabled child is born, there is a divide in family life that divides life before and after disability (Vaičekuskaitė & Kreiviniene, 2017). Without timely professional help, the family experiences complex emotional-psychological processes that lead to social isolation. Due to the constant childcare, parents are not able to participate in the labor market processes. Often parents balance at the financial and emotional limit, forgetting their needs as parents. The solution of social problems and the increase of services for families raising children with disabilities depend on the country's national policies, implemented practices and the development of an inclusive society.

Šumskienė and Pūras (2014) examine issues of social inclusion. Ruškus (2020) analyzes the rights of the disabled. The quality of social services and management processes are studied by Dunajevs & Žalimienė (2014), Gečienė & Raišienė, (2018). Aidukaitė & Senkuvienė (2019) believes that Lithuania applies a social support model when financial support almost always (except for child benefit) depends on family members' income. Therefore, the problem of meeting the need for social services remains a particularly relevant problem in Lithuania (Grigužauskaitė and Skučienė, 2019), which is one of the most relevant in organizing and providing services to families. Foreign authors, Williams et al. (2020) believe that help is needed, e.g. a balanced lifestyle is important for families (Finger et al., 2019), such opinions and Rapolienė et al. (2017) with a child with a disability (McConkey et al., 2021; Itagiba et al., 2019) participation in employment activities and this responds to family relationships and emotional well-being.

Often, the management of social services in a country reflects the implementation of state social policy in practice. Government representatives who influence social policy and make responsible decisions can contribute to the development of an inclusive society in their country (Blanck, 2020). It is observed that the paradigms of disability and inclusion emerge from more developed countries, which aim to adapt individual needs to people with disabilities, their families and make a strong contribution to fostering an ideology of social justice (Swanwick et al., 2020).

The relevance of the topic is determined by the increased need for social services in Lithuanian municipalities and the development of new forms of social services in order to achieve more optimal and efficient management. There are also systemic problems when it comes to the lack of a unified information system on the level of disability found for children. It is also noted that until a family raising a child with a disability applies for social services, municipalities do not have the opportunity to determine the need for social services, nor can they plan funding for the provision of social services. This field has not been sufficiently

researched in Lithuania, therefore the article applies the method of analysis of scientific literature, based more on the best practices of foreign countries.

While analyzing the literature reviews, we try to answer the question, what is the practice of social services for families with disabled children in Lithuania? The article will help to identify the main features of the provision of social services and the possibilities of assistance to families raising children with disabilities.

Peculiarities of social services management

Social services as a means of assistance to persons who are unable to take care of themselves, and the state creates conditions by creating them (Dvarionas et al., 2014). The proper organization and delivery of services requires systematic, targeted management. Research sources single out four core values of service management in the public sector: professionalism, efficiency, service, and engagement, which are based on compatibility and adaptability to client needs (Rose et al., 2015). Often, the organization of services depends on a valuable organizational environment and available financial resources (Friedländer et al., 2021).

Peculiarities and practices of social services are inseparable from the public administration sector, the achievements of which depend on the relationship between citizens and government (Rose et al., 2015). Although civil servants in the public sector are sometimes seen as structured and authoritative bureaucrats, the development of services is still considered to depend on their professionalism, value positions, management model (Ranerupa & Henriksenb, 2019). Rose et al. (2015) believe that the management and organization of social services depends on the values of public sector managers. This is because social services are designed for people experiencing social exclusion, difficulties with individual attention.

The experience of foreign countries shows that it is focused on the professionalism and competencies of employees at all levels of management (Ranerupa & Henriksenb, 2019; Rose et al., 2015). Research shows that the quality of social services depends on the highest level of administration and employees directly providing social services, as well as on cross-sectoral cooperation (Nordesjö, 2020). Gečienė and Raišienė (2018) state that cooperation is important at all levels to ensure purposeful provision of services. In the provision of social services, the principle of cooperation is equal to the involvement of the recipient of the service. For example, the principle of subsidiarity in force in Germany encourages the involvement of non-governmental organizations in the management of services, which promotes competitiveness and guarantees the quality of services (Friedländer et al., 2019).

Researchers note that high-quality services reduce even administrative costs (Ranerupa & Henriksenb, 2019). However, Gečienė and Raišienė (2018) believe that the quality of social services, assessed in terms of their rationality, efficiency and cheapness, does not necessarily ensure the quality of life of people receiving services. It is therefore very important that services are personalized and meet individual needs. For example, comprehensive and systematic assistance would ensure the proper functioning of the service recipient in the future and in the present.

Support opportunities for families raising children with disabilities

In countries where policies are more focused on solving social problems, citizenship, and developing social responsibility, the delivery of social services is more effective (Swanwick et al., 2020). One of the most important indicators of the country is considered to be social inclusion (Ramaškienė & Šumskienė, 2020; Dwyer et al., 2019). The availability of assistance is believed to reflect the state's ability to care for more vulnerable groups.

Disability covers a wide range of physical and mental disorders, thus limiting human activities and opportunities to participate in community life (Rigles, 2019). One of the aid measures that helps to strengthen the independence of a person with a disability is the provision of social services. The concept and goals of social services are focused on individual and family support processes. A person's disability can be both physical and psychosocial, in both cases individual or complex assistance is required. Children with disabilities are dependent on their parents and other family members, so the topic of disability and help options is becoming increasingly relevant in scientific discourse.

Every family raising a disabled child faces many problems. First, they are overwhelmed by the diagnosis. Families often experience a situation of ambivalence that divides life before and after disability (Vaičekauskaitė & Kreiviniienė, 2017). It's like a label or a sentence that determines the future life of a child and the whole family. Social services are becoming a source of support and help for the family.

It is noticeable that social support is increasingly becoming an alternative to social services in the material sense. However, it should be noted here that e.g. incapacity benefits or support money for raising a child with a disability are not an appropriate means of reducing social exclusion. This requires employment, access to services, and family participation in labor market processes (Dwyer et al., 2019). Absence from the labor market, lack of comprehensive assistance directly affects the emotional and psychological health of the family. E.g. countries such as Sweden, USA, Germany pay more attention to the emotional well-being of the whole family, the importance of social isolation and the adaptation of individual services.

Studies show that comprehensive support for parents strengthens emotional resilience and improves relationships with a child with a disability (McConkey et al., 2021). In terms of adequacy of services, it is important that the whole family receives the necessary support in a timely manner. For example, a child with a disability would receive special pedagogical (speech therapist, special pedagogue, typhlopedagogo, surdopedagogo) social assistance, psychological and, if necessary, medical services at all stages of development. Parents need help and education in raising a child with a disability (Itagiba et al., 2019; Swanwick et al., 2020). Finally, psychological and emotional imbalances in the family may result from insufficient attention to the health of the parents themselves (Williams et al., 2020). These processes are important for the full functioning of the family.

It is important to note that children's day care centers are a particularly important source of support for families raising children with disabilities. Studies in the US have shown that a child in a family receiving community help is employed, as are children of normal development, parents participate in labor market processes, follow a daily routine, and appear to be successful in social life (McConnell et al., 2015). It is noted that appropriate services based on the individual needs of the family and the child reduce the problems of social exclusion (Itagiba et al., 2019). Social services are considered to be one of the support measures for a family raising a disabled child. On the other hand, in order to improve the

quality of life of families raising a child with a disability, services are needed that cover a wide range and different areas.

Accessibility of social services in Lithuania for families raising children with disabilities

The prevailing family support model in Lithuania covers three main areas: health, education and social. Systematic service management can ensure the planning and delivery of assistance to children with disabilities and their parents. Accessibility of social services for children with disabilities is regulated by the Government of the Republic of Lithuania Regulation 2019. Regulations. June 19 Resolution no. 618 “On Approval of the Package of Basic Services for the Family”, Law on Social Services of the Republic of Lithuania (2006), Catalog of Social Services of the Republic of Lithuania (2006), Order of the Minister of Health of Lithuania on local rehabilitation and organization of sanatorium. The Law on Social Services of the Republic of Lithuania regulates eight principles aimed at developing and strengthening the abilities of a person or family, solving problems independently, participating in public life and overcoming social exclusion (Law on Social Services of the Republic of Lithuania, 2021). The main social services provided in Lithuania are presented in Figure 1.



Source: Lithuanian Social Services Catalog, 2006.
Figure 1. Social services for families with disabled children

The systematic organization and delivery of social services requires effective management that meets the individual needs of the service recipient. The problem of meeting the need for social services is one of the most relevant in organizing and providing social services. In Lithuania, the focus of institutions is on finding help for a disabled child in the field of education, the issues of access to services are analyzed, but little attention is paid to the well-being of parents. The need for assistance has also increased in Lithuanian municipalities, and new forms of social services are being developed in order to achieve more optimal and efficient management. It is noticeable that the state is looking for solutions, ways to help families with children with disabilities. However, due to the lack of specialists and the lack of a unified service management mechanism, the situation remains difficult and does not meet the needs of both parents and children (Grigaitė & Jurevičiūtė, 2020).

As the experience of foreign countries shows, an important source of support for the family is services in the community, which promote the involvement of the family in community activities, provide employment services for the child and thus reduce the social exclusion of the whole family. One such tool is community day centers. It is noted that in Lithuania in 2019, 2653 children with disabilities attended children's day care centers, which is 12.2% disabled children from all over Lithuania (SADM, 2021).

In Lithuania, the legal framework for social inclusion, medical, educational and psychosocial assistance for children with disabilities has been developed, but there is a lack of a targeted system of measures to enable families affected by disability to realize their potential, maintain good psychosocial health and ensure full social participation (Piščalkienė & Navickienė, 2019). It is important to note that the role of non-governmental organizations, which also represent families raising disabled children, is strengthening in Lithuania (SADM, 2021). Targeted and systematic management of services can ensure the planning and provision of assistance to children with disabilities and their parents.

Methodology of investigation

The method of systematic comparative literature analysis aims to collect, systematize and analyze the obtained data in the chosen field. A systematic analysis of the scientific literature was performed in order to determine the peculiarities and practices of the provision of social services to families raising disabled children. In order to single out the scientific literature related to the research topic, the research questions were formulated: TK1: What are the good practices in other countries in providing assistance to families raising children with disabilities? TK2: What is the situation in Lithuania for families raising children with disabilities?

Academic literature search was performed using Google Scholar search engine for other platforms. The study was conducted in two phases. The following keywords were used for the initial search: disability, family, social services, accessibility, social inclusion, needs of parents raising children with disabilities, employment of children with disabilities. During this selection, 22 articles by Lithuanian and foreign scholars were found. In the second stage of the research, after reviewing the full text of each selected publication and rejecting those publications that did not meet at least one of the research selection criteria (scientific article in a scientific periodical; full article; published since 2015; publication related to the research topic) 10 articles were selected for analysis.

After analyzing the scientific literature, it was possible to identify the main features and practice of social services in foreign countries and Lithuania. The systematized results of the

study are presented in Table no. 1, and the summarized results of the study are presented in the model of social assistance services for families with disabled children (Figure 1).

Methods: systematic comparative analysis of peculiarities and practices of social services provision in Lithuania and abroad.

Results

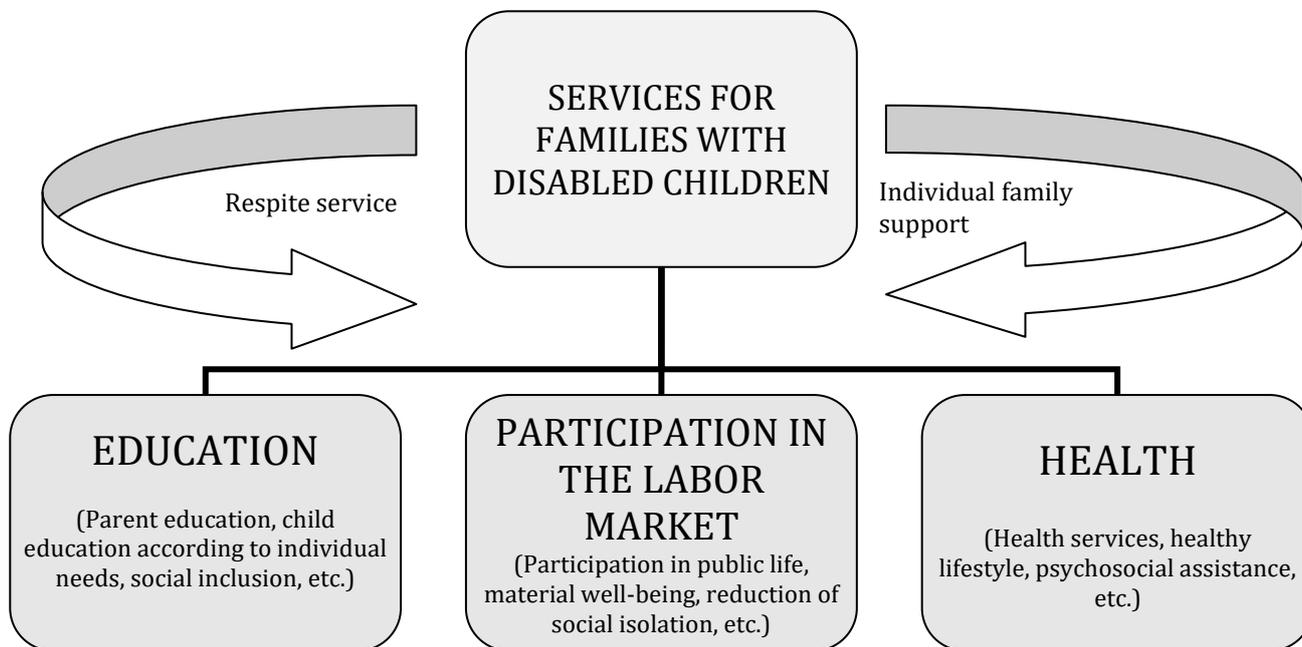
After the analysis of the scientific literature, the possibilities of help for families raising children with disabilities were determined (1 Table).

1 Table. Support opportunities for families raising children with disabilities

Possibility of assistance for families with disabled children		Authors	
Family health factors			
1.	the importance of a balanced lifestyle for the family;	Williams et al. 2020; McConnell et al., 2015; Rapolienė et al., 2017; Finger et al., 2019; Grigužauskaitė & Skučienė, 2019.	
2.	balanced lifestyle;		
3.	a healthy diet;		
4.	healthy lifestyle;		
5.	imbalance in the family.		
Social services			
6.	empowerment;	Dvarionas et al., 2014; Piščalkienė & Navickienė, 2019; Ranerupa & Henriksenb, 2019; Gečienė & Raišienė, 2018; McConkey et al. 2021; Vaičekauskaitė & Kreivinienė, 2017; Grigaitė & Jurevičiūtė, 2019.	
7.	individual customer needs;		
8.	service management;		
9.	quality of social services;		
10.	with disabilities;		
11.	comprehensive family support;		
12.	the social reality of raising a child with a disability;		
13.	comprehensive family support;		
14.	management of social problems.		
Participation in the labor market			
15.	inclusive society;		Dwyer et al., 2019; Aidukaitė & Senkuvienė, 2019; Brighton & Townsend, 2021; Ramaškienė & Šumskienė, 2020.
16.	dependence of financial support on family income;		
17.	social isolation;		
18.	social society stability indicators.		
EDUCATION IN FAMILY LIFE			
19.	Reducing social exclusion;	Stefanidis & Strogilos 2020; Dunajevs & Žalimienė, 2014; Swanwick et al., 2020; Itagiba et al., 2019.	
20.	quality of life of children with disabilities and their families;		
21.	social responsibility education;		
22.	providing assistance according to individual needs.		

After identifying the peculiarities of the provision of social services and families raising children with disabilities, the main indicators (1 table) necessary for organizing the family

support process have been clarified. The information is summarized and presented in the model of social assistance services for families with disabled children (see Figure 2).



Source: Compiled by the author

Figure 2. Model of social assistance services for families with disabled children

The analysis revealed that social services are part of the support process for a family raising a disabled child. It is important to note that families raising children with disabilities want to live in the same way as families raising children with typical development. In order to ensure the successful functioning of the family in the life of society, an assistance mechanism combining individual aspects is needed. Such as health, work, social services and education. For family life to be quality, there must be a balance between these areas. The public sector has an important role to play. The priority directions of the state that address the problems of social exclusion depend on political decisions. Thus, public decision-makers at both local and national level play an important role in the aid process.

Conclusions

An analysis of the literature has shown that families raising children with disabilities need comprehensive support to provide assistance in all areas of life, as has been achieved in other countries. The adaptability and adequacy of services would ensure social inclusion processes, financial sustainability and participation in labor market processes. We note the need to improve the systematic assistance mechanism of social services among institutions providing assistance to families raising children with disabilities. The analysis of foreign and Lithuanian scientific sources revealed the directions of assistance that would ensure the successful functioning of the family in the life of society: health, work and education. Based on these results, we can say that social services alone are not enough for a quality family life, this requires systemic assistance that would improve the quality of life and participation of parents and children with disabilities in society.

References

- Aidukaitė, J., Senkuvienė, K. (2019). The family support system in Lithuania: Experts' views and citizens' evaluation. *Problemy Polityki Społecznej*, 47 (4) : 29–46. DOI: <https://doi.org/10.31971/16401808.47.4.2019.2>.
- Blanck, P. (2020). Disability Inclusive Employment and the Accommodation Principle: Emerging Issues in Research, Policy, and Law. *Journal of Occupational Rehabilitation*, 7, 30, 505–510. DOI: <https://doi.org/10.1007/s10926-020-09940-9>.
- Dunajevs, E., Žalimienė, L. (2014). Tructure of social assistance in Lithuania from the perspective of the client's autonomy and paternalism. *Social work. Experience and methods*, 14 (2), p. 37-54. <http://dx.doi.org/10.7220/2029-5820.14.2.3>.
- Dvarionas, D., Motiečienė, R., Ruškus, J., Mažeikienė, N. ir Naujanienė, R. (2014). The model of empowering social services in the context of social welfare policy. *Philosophy. Sociology*, 25 (2), p. 89–97.
- Dwyer, P., Scullion, L., Jones, K., McNeill, J., Stewart, A.B.R. (2019). Work, welfare, and wellbeing: The impacts of welfare conditionality on people with mental health impairments in the UK. *Social Policy & Administration*, vol. 54, 2, 311 – 326. DOI: 10.1111/spol.12560.
- Finger, J., F., Busch, M. A., Heidemann, C., Lange, C., Mensink, G. B. M., Schienkewitz, A. (2019). Time trends in healthy lifestyle among adults in Germany: Results from three national health interview and examination surveys between 1990 and 2011. *PLOS ONE*. Vol. 14, No. 19. <https://doi.org/10.1371/journal.pone.0222218>.
- Friedländer, B., Röber, M., Schaefer, C. (2021). Institutional Differentiation of Public Service Provision in Germany: Corporatisation, Privatisation and Re-Municipalisation. *Public Administration in Germany*, 291-309. DOI: https://doi.org/10.1007/978-3-030-53697-8_17.
- Gečienė, J., Raišienė, A.G. (2018). Service Quality of Organizations Providing Long- Term Social Care. *European Scientific Journal*, vol.14, 26. Doi:10.19044/esj.2018.v14n26p1.
- Grigužauskaitė, S., Skučienė, D. (2019). Legal preconditions for reconciling family and work in Baltic states. *Social work. Experience and methods*. Vol. 18, 8–22. DOI: <https://doi.org/10.15388/STEPP.2019.1>.
- Grigaitė, U., Jurevičiūtė, G. (2020). The results of the activities of the social integration of people with disabilities and the implementation of the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol in 2019 monitoring report. Human Rights Monitoring Institute. http://www.ndt.lt/wp-content/uploads/ZTSI_ataskaita_po-pastabu_FINAL.pdf.
- Itagiba, R. M., Pereira, R., Silva, N. L., Crolman, S., Almeida, S.R. (2019). Family functioning and social support network: families with children with down syndrome. *Gerai: Revista Interinstitucional de Psicologia*, 12 (1), 142 – 158. DOI: 10.36298/gerais2019120111.
- Law on Social Services of the Republic of Lithuania. 2006 January 19 No. X-493.
- Lithuanian Association of the Disabled (2019). Research on Ensuring the Rights of a Disabled Child and Family Assistance, Assessing the Effectiveness of Implementing the Provisions of the United Nations Convention on the Rights of Persons with Disabilities in Lithuania. <http://www.ndt.lt/neigaliuju-teisiu-konvencija/tyrimai/tyrimai-2019-m/>.
- McConkey, R., Pauline, O., Corcoran, J. (2021). The need for and the impact of a family-centred intervention for parents of children with developmental disabilities: A model project in rural Ireland. DOI: 10.3390/ECERPH-3-09023.
- McConnell, D., Savage, A., Breikreuz, R., Sobsey, D. (2015). Sustainable Family Care for Children with Disabilities. *Journal of Child and Family Studies*. DOI: 10.1007/s10826-015-0245-0.
- Ministry of Social Security and Labor of the Republic of Lithuania. Statistics, 2021. <https://socmin.lrv.lt/lt/veiklosritys/socialine-integracija/neigaliuju-socialine-integracija/statistika-2>.
- Nordesjö, K. (2020). Framing Standardization: Implementing a Quality Management System in Relation to Social Work Professionalism in the Social Services. *Human Service Organizations: Management, Leadership & Governance*, 44:3, 229-243, DOI: 10.1080/23303131.2020.1734132.
- Piščalkienė, V., Navickienė, L. (2019). Measures for children with disabilities and their parents mental social health and social inclusion improvement, need and benefits. *Health sciences in Eastern Europe*. Vol. 29, No. 6, 5-11. DOI: <https://doi.org/10.35988/sm-hs.2019.089>.
- Ramaškienė, L., Šumskienė, E. (2020). The impact of social business on communities development of social capital. *Social theory, empiricism, politics and practice*. Vol. 21, 66–85. DOI: <https://doi.org/10.15388/STEPP.20.23>.

Ranerupa, A., Henriksen, H. Z., (2019). Value positions viewed through the lens of automated decision-making: The case of social services. *Government Information Quarterly*, 36, 101377. DOI: <https://doi.org/10.1016/j.giq.2019.05.004>.

Rapolienė, L., Eigelytė, A., Gedrimė, L., Norkienė, S., Sąlyga, J. (2017). Population awareness of healthy living. *Health sciences in Eastern Europe*. Vol. 27, No. 6. DOI: <https://doi.org/10.5200/sm-hs.2017.100>.

Rose, J., Persson, J.S., Heeager, L.T., Irani, Z. (2015). Managing e-Government: value positions and relationships. *Info Systems J*, 25, 531–571. DOI: 10.1111/isj.12052.

Rigles, B. (2019). The Development of Health Lifestyles in Families Experiencing Disability. *Journal of Family Issues*. Vol. 40, No. 7, 929–953. DOI: 10.1177/0192513X19831410

Ruškus, J. (2020). Grupinio gyvenimo namuose daugiau žmogaus teisių neatsiranda. *Socialinis darbas. Patirtis ir metodai*, 25 (1), 113–119. DOI: <https://doi.org/10.7220/2029-5820.25.1>.

Swanwick, R., Oppong, A.M., Offei, Y.N., Fobi, D., Appau, O., Fobi, J., Mantey, F.F. (2020). The impact of the COVID-19 pandemic on deaf adults, children and their families in Ghana. *Journal of the British Academy*, 8, 141–165. DOI <https://doi.org/10.5871/jba/008.141>.

Šumskienė, E., Pūras, D. (2014). Eikit pažiūrėkit, kaip neturi būti: psichikos sveikatos politikos raida ir jos rezultatai. *Socialinis darbas. Patirtis ir metodai*. 13 (1), 75-90.

Vaičekauskaitė, R., Kreivinienė, B. (2017). Scientific reconstruction of the reality of a family raising a child with a disability. *Tiltai*. Vol. 3, 39–50. DOI: <http://dx.doi.org/10.15181/tbb.v77i2.1599>.

Williams, K., Jacoby, P., Andrew Whitehouse, A., Kim, R., Epstein, A., Murphy, N., Reid, S., Leonard, H., Reddihough, D., Downs, J. (2020). Functioning, participation, and quality of life in children with intellectual disability: an observational study. *DMCN Developmental Medicine & Child Neurology*. Vol. 63, No. 1. DOI: <https://doi.org/10.1111/dmcn.14657>.



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