

AVAILABILITY OF SERVICES FOR FAMILIES OF CHILDREN WITH DISABILITIES IN LITHUANIA BY VIEW OF HEADS OF SOCIAL, HEALTH AND EDUCATION INSTITUTIONS IN THE ALYTUS REGION

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Abstract. *Family support is a crucial component affecting the functioning of parents of children with disabilities within society. Sufficient services that cater to both child support and the parents' quality of life are required, or else the state labor market runs the risk of losing able-bodied citizens who are responsible for raising children with disabilities. Thus, the research has twofold aim: to review the system of public services for families raising children with disabilities in Lithuania, and to analyze the availability of services from the perspective of managers of service-providing institutions. A structured interviews was conducted to collect information from eighteen experts who are heads of education, health and social services departments of municipalities and subordinate institutions, responsible for decision-making in the organization and provision of services to families raising children with disabilities in the Alytus region. According to research findings, the Alytus region has the potential to provide education, healthcare, and social services following legal provisions. However, the current range of services is inadequate in practice. Typically, most services are available only upon parental request for children with disabilities, with certain services not being available for numerous reasons. Based on the research findings, the insufficient provision of services in the Alytus region is mainly attributable to a shortage of service staff and limited financial resources. At the same time, the study highlights a slow responsiveness of the municipalities and their subordinate entities towards communicating and collaborating, as well as with parents of disabled children.*

Keywords: *availability of public services; families of children with disabilities; social inclusion; family-centred social policy; municipalities; Lithuania.*

Reikšminiai žodžiai: *viešųjų paslaugų prieinamumas; vaikus su negalia auginančios šeimos; socialinė įtrauktis; į šeimą orientuota socialinė politika; savivaldybės; Lietuva.*

Introduction

State services for families raising children with disabilities are essential to enable them to function effectively in society. The birth of a child with a disability changes the entire family dynamic, altering both parental responsibilities and commitments. In many cases, one of the parents gives up his or her career to care for the child (Samsonienė, 2017), putting the family on the edge of social and economic survival (Piščalkienė, 2019; Grigaitė, 2020). To retain working citizens in the labor market, families of children

with disabilities (CWD) require a diverse range of services tailored to both the children and their parents. Despite the significance of services to families of CWD and to the national economy, the sufficiency, availability, and accessibility of services are understudied by both researchers and service providers. The knowledge gap is relevant in many countries. Hu (2022), Bourke-Taylor (2021), Stefanidis (2022), and others have emphasized the need for research to prioritize the importance of providing comprehensive support to families of CWD and to dispel the idea that meeting the needs of children with disabilities is synonymous with meeting the needs of families raising CWD.

Assistance for families with CWD is provided in Lithuania in the areas of social services, health and education. However, almost all services are focused on helping the child, while the needs of the family, and especially the parents, are often overlooked. Support for parents of CWD is integral to the wellbeing of all family members (Dizdarevic, 2020; Chastang, 2022; Staunton et al., 2023; Fu et al., 2023). Whereas untimely assistance negatively impacts family relationships and leads to various health disorders among family members (Akavickas, 2021; Baranauskienė, 2021; Savari et al., 2023). In other words, a lack of services for families raising CWD can increase the risk of social exclusion for the entire family. Therefore, the paper aims to review the system of services for families raising children with disabilities in Lithuania, and to examine the availability of services from the perspective of managers of service-providing institutions.

Since services for families with CWD are planned and provided by the municipal departments and subordinate institutions, the interview with managers can reveal how the professionals on whom the range and availability of services depend perceive their role and the contribution of their organization. With this task in mind, structured interviews were conducted and information from eighteen experts was collected. Officials from education, health, and social services departments in municipalities and subordinate institutions with responsibility for decision-making related to organizing and providing services for families raising children with disabilities in the Alytus Region, Lithuania, shared their views.

The article is divided into three main sections: a theoretical examination of the state service system for families with CWD, a presentation of the empirical research methodology, and an analysis of the research results. The research findings are summarized in the conclusions section.

Public services for families raising children with disabilities: some highlights

Parents of CWD face unique challenges compared to parents raising children with typical development. It has been established that parents provided with greater support experience lower parenting stress and vice versa (Zhao, 2021; Savari et al., 2023). Unfortunately, assistance and support systems for families raising CWD are not always adequate, responsive to circumstances, or contemporary. As a result, some countries have developed specific procedures aimed at continuously assessing service needs and accessibility. For example, in the United Kingdom and the Netherlands, there is a centralized system of services for families, the effectiveness of which is regularly analyzed (Johansson, 2020). Meanwhile, in Sweden, a model is applied that ensures interventions support service quality: services are provided systematically, continuously developed and evaluated, and maintain order from input to output according to client needs (Nordesjö, 2020). Other Nordic countries emphasize more on the “enabling policies” model, where services are planned in the long-term perspective. Developing the “enabling policies” model aims to educate parents better, foster their independence, provide childcare services, and offer financial support (Cantillon, 2021).

In addition, in many countries, parents of CWD have the right to request that their child’s needs be assessed by social services. This is the first step in determining what kind of assistance and support the family may require. Parents’ ability to request support and express family needs fosters stronger parental independence and better understanding of the country’s service system capabilities (Huus, 2017; Fu et al., 2023). Conversely, families raising CWD who avoid seeking support often opt for informal sources of support (Park, 2022). These informal sources may not be as effective as public services.

Generalizing, there exists a range of services and organizational models for families with CWD available in various countries (Figure 1).

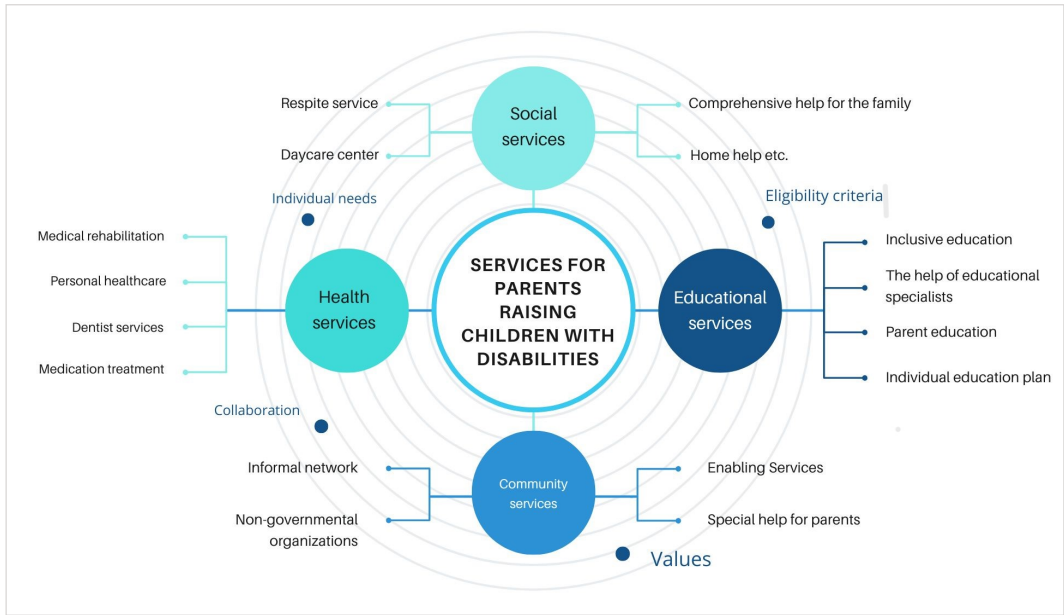


Figure 1. Theoretical perspective on the service system for families raising children with disabilities.

Source: Compiled by the authors, based on Huus, 2017; Nordesjö, 2020; Johansson, 2020; Zhao, 2021; Cantillon, 2021; Park, 2022; Fu et al., 2023; Savari et al., 2023).

For the state-provided service system to be effective for families raising CWD, it is crucial to address the needs of both the child and the other family members. Nevertheless, there is a lack of both research and practice on this issue.

State-provided service system for families raising children with disabilities in Lithuania

Social services

In Lithuania, social services aimed at preventing the emergence of social risk for individuals, families, or communities or aiding a person or family due to age, disability, social risk, etc., are regulated by the Catalogue of Social Services (Dėl Socialinių paslaugų [...], 2022).

The basic service package for families consists of 14 services (see figure 2) (Dėl Socialinių paslaugų [...], 2022). The country's municipalities are responsible for providing these services. They must identify the needs of families and ensure that they receive the necessary services. If a specific service is not provided in the municipality, the municipal administration must organize transportation and ensure that the service is provided in another municipality (Dėl [...], 2022).

Despite the advantages, there are shortcomings in the social services sector. The report of the Ombudsman for the Protection of the Rights of the Child for the year 2021 indicates that 75% (45 out of 60) of municipalities do not analyze information on the need for service development for parents whose child

has been identified with a protection or family and child support need. The report notes that not all social services for families are analyzed in the municipal social service plans, and 27% of all municipalities did not provide some of the basic services for children or parents specified in the legal acts. Municipalities cited a lack of funding and infrastructure deficiencies as the reasons (Lietuvos Respublikos vaiko teisių [...], 2022).

On the other hand, there is a clear management issue: in 2021, each municipality, together with non-governmental organizations and other social partners, had to perform a service accessibility analysis. Unfortunately, only 10 municipalities assessed the need for additional/new social services and planned steps for the development of services for families with disabled children. In the remaining 50 Lithuanian municipalities, such a need for social services was not assessed. As a result, it is understandable that families with disabled children may lack services.

Health Services

Health services in Lithuania for families with disabled children are provided according to areas of activity such as personal health care, public health care, and others. Services for families with disabled children are provided in medical institutions, public health offices, and private sectors.

In Lithuania, family medicine services are more focused on solving health problems rather than strengthening or preserving health. Moreover, the services provided by family doctors, dentists, and mental health specialists have not been coordinated at the patient level, and their provision is still not systematic. A family doctor, pediatrician, or other specialist physician, having identified a child's developmental disorder or developmental disorder risk, can refer patients to a physician providing early rehabilitation services for children with developmental disorders (Lietuvos Respublikos sveikatos apsaugos [...], 2023).

Families with CWD can also take advantage of medical rehabilitation services. Medical rehabilitation is a comprehensive set of medical rehabilitation methods, such as physiotherapy, occupational therapy, clinical speech therapist services, selection and adaptation of orthopedic and technical aids, psychological and social support, therapeutic massage, physiotherapy, drug treatment and diet, and training of patients and their relatives (Dėl vaikų raidos sutrikimų [...], 2018). It is important to note that after completing medical rehabilitation, parents receive knowledge and information about the child's disability and adaptation to it (Dėl medicininės reabilitacijos [...], 2022).

Finally, preventative healthcare occurs at the local government level, with public health offices providing these services. It is pertinent to note that health specialists operate in educational institutions and must give special consideration to children with individual needs in accordance with applicable legal provisions.

Education Services

According to Article 24 of the United Nations Convention on the Rights of Persons with Disabilities, children with disabilities have the right to learn, develop their skills, and talents. Due to disability, children cannot be excluded from schools or other educational institutions; they have the right to acquire free compulsory primary or secondary education. The Convention on the Rights of Persons with Disabilities states that learning conditions must be adapted to the specific needs of a child with a disability, and parents must be informed about it. However, parent surveys show that it is difficult to find a mainstream school adapted for children with disabilities (Raudeliūnaitė, 2022). The situation in quantitative terms is good: currently, about 90% of children with special educational needs study in mainstream classes and kindergarten groups with their peers. Unfortunately, to ensure the successful functioning of a child with a disability in society, parents face obstacles and challenges in ensuring proper inclusion in educational institutions.

Summarizing the availability of social, education, and health services for families with children with disabilities according to the current legal framework, the opportunities for assistance for the child are quite extensive. However, these services are less oriented towards providing support to the family members or parents of the child with a disability (Figure 2).

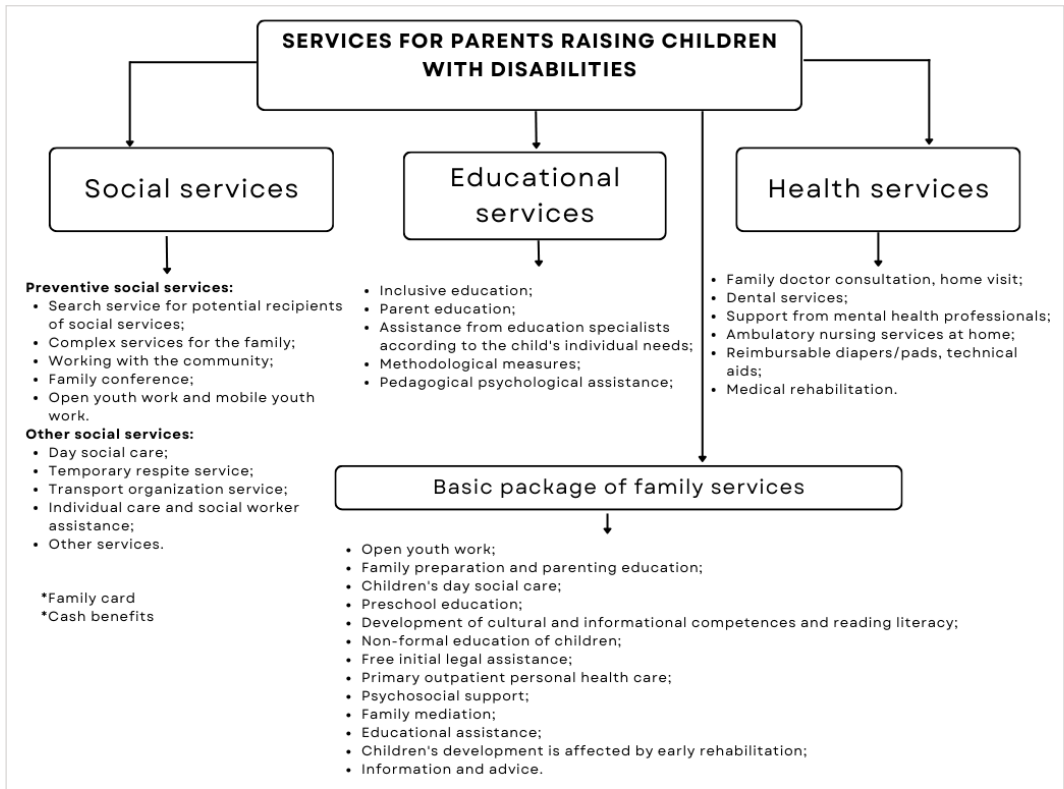


Figure 2. Services for families raising children with disabilities in Lithuania.

Source: Compiled by the authors.

In Lithuania, there is an Inclusive Education Center that provides individual counseling to students, their parents, and teachers (Įtaukties švietime plėtros gairės, 2022). According to the legal regulation, parents of children with disabilities must participate in providing all educational psychological support and be part of the school team. Parents are especially important participants in providing education services to children with disabilities.

As can be seen, the current legal acts governing the accessibility of social, educational, and health services for families with children with disabilities provide a relatively broad scope of assistance for the child. Still, their focus on supporting the family members or parents of the disabled child remains weak. Furthermore, although there are legal provisions and other official documents that suggest that children with disabilities in Lithuania should receive extensive assistance, the activity report of the Child Rights Protection Controller of the Republic of Lithuania in 2021 (Lietuvos Respublikos vaiko teisių [...], 2022) casts doubt on the system's efficacy. To determine the factors contributing to the insufficiency in the availability and accessibility of government services for families with CWD, we conducted interviews with the heads of social, educational, and healthcare institutions within the municipalities of Alytus Region. The outcomes of these interviews are outlined below.

Methodology

There are a total of 10 regions in Lithuania, encompassing 60 municipalities. The chosen region for the study is the Alytus region, which includes four municipalities – Varėna District Municipality, Druski-

ninkai Municipality, Lazdijai District Municipality, Alytus City Municipality and Alytus District Municipality. For the research, the Alytus region was chosen to represent the Lithuanian context. Notably, the distribution of municipalities within this region that have assessed the sufficiency of public services for families with CWD compared to those that have not conducted an assessment reflects the national situation. In Lithuania, just 10 out of the 60 municipalities have evaluated the sufficiency of education, health-care, and social services for families who raise children with disabilities. One of the four municipalities in the Alytus region has conducted the aforementioned analysis. Thus, the Alytus region has the potential to serve as a representation of the situation throughout the country.

The research included 18 leaders of education, health and social services departments and institutions in the municipalities of the Alytus region, who are responsible for decision-making in the organization and provision of services to families raising CWD. During the interview, we aimed to collect information regarding the availability of services, the involvement of stakeholders in decision-making, and the availability of assistance in municipalities for families with children with disabilities.

Research data was collected in March-April 2023. Verbal consent to participate in the study was obtained from all participants and is stored with the interview data in an audio file in a password-protected folder by the authors of this study. When reporting the results of the interviews in the paper, the interviewees were coded with a letter C followed by a unique number of the informant. This anonymization approach maintains the confidentiality of the participants. When presenting the findings of the study in the paper, the sectors represented by the interviewees are indicated by abbreviations: education services (ES), social services (SS) and health services (HS) (Table 1). In this way, ethical principles of the research were respected.

Table 1. Information on study participants

No.	Municipality	Position	Represented Service Area
1	A	Head of the Education Department (C ¹)	EP (Education Services)
2		School Principal (C ²)	EP
3		Head of the Social Support Department (C ³)	SP (Social Services)
4		Municipal Doctor (C ⁴)	HSP (Health Services)
5		Head of the Public Health Office (C ⁵)	HSP
6	B	Head of the Education Department (C ⁶)	EP
7		School Principal (C ⁷)	EP
8		Head of the Public Health Office (C ⁸)	HSP
9		Head of the Social Support Department (C ⁹)	SP
10	C	Head of the Education Department (C ¹⁰)	EP
11		School Principal (C ¹¹)	EP
12		Municipal Doctor (C ¹²)	HSP
13		Head of the Public Health Office (C ¹³)	HSP
14		Head of the Social Support Department (C ¹⁴)	SP
15		Head of the Social Services Center (C ¹⁵)	SP
16	D	School Principal (C ¹⁶)	EP
17		Head of the Education Department (C ¹⁷)	EP
18		Head of the Social Support Department (C ¹⁸)	SP

A structured interview was the method for collecting research data. During the interview, six open-ended questions were posed: 1) What services in your represented area (education, health or social) for families with CWD are provided in the municipality? 2) Has a needs analysis been conducted in your area for a service catering to families with CWD? 3) How frequently and in what circumstances do parents of CWD contact your institution for services? 4) How is information about the institution's services conveyed to families with CWD? 5) How is it determined which services CWD families lack? 6) How is collaboration between service provider institutions and decision-making institutions for service development and funding carried out? The questions were initially presented orally and subsequently sent to participants by email, requesting comprehensive written responses.

The data collected has been analyzed using content analysis. The findings from the research are displayed in tables and written form throughout the paper.

Research Results

Initially, the analysis was focused on the provision of educational services for families with CWD. According to interview results, institutions are theoretically capable of providing services as required by legal acts; however, the availability of educational services is limited by constraints in four areas: lack of inter-institutional cooperation, lack of cooperation with CWD parents, lack of funding for services, and lack of specialized skills in educational institutions (Table 2).

Table 2. Availability of education services for families with CWD

Category	Subcategory	Supporting Quotes
Advantages of Education Services for Families with CWD	Institutions are prepared to provide services mandated by law	"[Provided] general and non-formal education services" (C ¹); "[Implemented] educational assistance - special pedagogical, social pedagogical, speech therapy, psychological <...> summer rest programs" (C ⁹); "A family centre has been established where assistance is provided, and family employment is organized" (C ⁶); "[There are] non-formal education groups organized by non-governmental organizations" (C ²); "Psychological well-being enhancement services are offered - individual consultations or group activities led by a psychologist" (C ⁷).
Constraints of Education Services for Families with CWD	Insufficient inter-institutional cooperation	"I had to cooperate only in one case" (C ⁶); "I don't know because I haven't participated in any format of cooperation events" (C ¹⁰); "First of all, communication between all responsible institutions and dissemination of information is needed" (C ⁶).
	Lack of cooperation and communication with parents of CWD	"[Parents] rarely contact the municipality" (C ¹); "Very rarely <...> over 5 years, when I work as a director, one mother contacted me" (C ⁷); "They contact us infrequently, 2-4 parents per year" (C ¹⁵).
	Limited funding for services	"There should be more funding and assistance for teachers who want to retrain as special educators" (C ²); "The school environment and shelter are not adapted for children with movement or other disorders and disabilities" (C ³); „Everything depends on the allocated funding“ (C ⁶).
	Shortage of specialists	„There is a lack of employment centers and employees who would provide non-formal education services offered by functioning institutions.“ (C ⁹); „Competent teachers' assistants (rather than those with only a secondary education from the streets)“ (C ²).

The study showed that educational institutions provide non-formal and general education assistance to CWD and identify it as the main activity for this group of education service recipients. Regional municipalities pay varying attention to discussing problematic situations and searching for solutions - some organize meetings periodically, for example, every month, while in other municipalities, meetings to discuss current issues of activities do not take place at all. It turned out that meetings are organized more frequently in the education departments of the surveyed municipalities and less frequently in the education institutions subordinate to municipalities. In other words, service providers and decision-makers have poor collaboration. Respondents emphasized the importance of parents' role in applying for service accessibility, but cooperation between education service providers and CWD families is weak. On the one hand, education department and school leaders noted that parents of CWD rarely apply for educational services. On the other hand, according to survey participants, parents have the freedom of choice, which they use irresponsibly: they do not follow the recommendations of specialists, making cooperation between specialists and parents difficult. Meanwhile, parents who apply to the municipality usually seek the services of a speech therapist, occupational therapist, physiotherapist, psychologist, special educator, or personal assistant. Unfortunately, there is a shortage of specialists. According to study participants, there is a lack of special assistance specialists, employment specialists, or competent teacher assistants. Respondents identified insufficient state funding for education and improper municipal budget allocation, where priority is not given to the provision of educational services in the municipal activities' portfolio, as the cause of the problem.

Next, the interview results in the field of health services provided to families with CWD were analyzed. According to the legislation, municipalities should ensure rehabilitation, primary and secondary health care services, as well as mental health care services for families raising CWD. Despite this, in most regional municipalities, these services are not actually provided, and the need for services is not investigated. Services are given only when parents apply for them themselves.

Information dissemination about health services for families with CWD is also limited. Parents can learn about available services on the websites of the municipality or health care institutions, from brochures distributed in health institutions, or by communicating with other parents of CWD. Thus, access to health services for families with CWD is complicated, institutions only formally offer services regulated by legal acts (Table 3).

When analyzing the availability of social services, it was revealed that preventive, general, and specialized services are provided to families with CWD in all regional municipalities. However, informants admit that there is a lack of inclusive children's day centers, self-help groups for parents, psychological and psychosocial support, and temporary respite services for parents raising CWD. On the other hand, not all shortcomings could be revealed during the study, as interview participants stated that comprehensive studies and analysis, which would help identify the need for social services, are not carried out in municipalities. As mentioned earlier, only one of the municipalities included in the research conduct a service needs assessment periodically.

Like educational services, social services for parents raising CWD are provided only when the family applies to the eldership, social assistance department, or other institutions. Meanwhile, information dissemination about social services for families with CWD is carried out passively in institutions. The main information channel about services for CWD remains communication in social networks, where parents share their experiences and institutions' websites. Parents can also consult with specialists about services, but overall, there is no unified and easily accessible information about social services provided by municipalities and their subordinate institutions (Table 4).

Overall, the interviews indicated that the educational, health, and social services for families with CWD are not provided as required by law and local regulations. The primary causes of service constraints include the slow distribution of information between institutions and families with CWD, inadequate collaboration within institutions and with parents of CWD, the shortage of service-providing professionals, and insufficient institutional funding.

Table 3. Availability of Health Services for Families with CWD

Category	Subcategory	Supporting Quotes
Advantages of Health Services for Families of CWD	Empowerment and inclusion of institution leaders in decision-making	“A meeting is organized every month with an external consultant - supervisor, so that each institution knows more specifically not only its functions and roles, but also the services provided by other institutions operating in the municipality <...> an algorithm for inter-institutional cooperation in the municipality is being created” (C1)
		“Cooperation between education, social and health sector specialists to expand and improve services for parents raising children with disabilities takes place on an ongoing basis by addressing current issues and problems directly, in the Child Welfare Commission, in the Non-Governmental Organization Council, by applying case management to families and participating institutions in joint training and supervision” (C13)
Constraints of Health Services for Families with CWD	Lack of services	“There are almost no services specifically for parents raising children with disabilities <...> only generally available lectures, psychologist consultations, exercise for adults are carried out” (C12)
		“We do not collect statistics on counseling for parents and/or children with disabilities” (C7)
		“There is a lack of occupational therapist, physiotherapist, neurologist, psychologist, special educator <...> there are no specialists at the national level” (C1)
	Involvement in providing health services	“There are requests from parents to accept children with disabilities into summer camps, but we do not have the opportunity to assign an assistant to such a child unless the parents participate together” (C12)
“If there are no specialists, the service is not provided in such a case <...> too much decision-making freedom is given to parents rather than competent specialists who write recommendations, which often remain only as recommendations” (C10).”		

Table 4. Availability of Social Services for Families with CWD

Category	Subcategory	Supporting Quotes
Advantages of Social Services for Families with CWD	Provided and organized services	“Children’s day social care, complex services for the family, personal assistant assistance, social care and rehabilitation in the disabled day center, ‘child +’ service, escort service for young people <...> services can be received by both healthy children and children with disabilities” (C13)
		“In the municipality, there is an opportunity to receive all social services that are regulated in the social services catalog” (C8)
		“Preventive services, general social services, special social services <...> the municipality organizes housing adaptation for children with disabilities” (C3)
		“General and special services <...> social care and social guardianship” (C14)

Category	Subcategory	Supporting Quotes
Constraints of Social Services for Families with CWD	Limited resources and resources	“There is a lack of inclusive children’s day centers, self-help groups for parents, psychological and psychosocial assistance.”
		“There is a need for psychologists to be attracted and trained in the preparation and implementation of training programs in the municipality.”
		“There is a lack of specialists speaking Russian.”
		“Temporary respite services.”
	Lack of service needs analysis	“Collecting and systematizing data on the number of children with disabilities according to the nature of disability and other indicators from publicly available sources <...> conducting surveys of residents, social service providers and various institutions on the need for social services.”
		“Parents or other persons contact us themselves.”
		“The need for social services for children with disabilities is determined by social workers in their place of residence.”
	Complicated accessibility of information	“Some parents <...> avoid contacting specialists, do not trust institutions and service providers or know little about what assistance might be due.”
		“Parents receive information about social services from the Disability and Working Capacity Assessment Service when a child is diagnosed with a disability <...> When submitting an application for targeted compensation, all information about social services is provided in the municipality <...> all information is provided by social work organizers working in wards.” “[Information can be found] on the Internet, in the press, through acquaintances.” “You can find out directly by contacting the ward, on the municipality’s website.”

Conclusions

The investigation has revealed that the educational, health and social services listed in the documents of the municipal institutions in the Alytus region comply with the legal requirements. However, families with CWD are often only able to access the services they need when parents take the initiative to proactively apply to the relevant agency; otherwise, the services might not be available to the clients altogether. Periodic surveys of parents raising children with disabilities are recommended to gauge the need for services. In addition, it is important to ensure improved availability of information about services provided in the municipality to families with CWD.

What is more, the study highlighted that insufficient staffing and limited institutional funding often result in a shortage of services for families with CWD. Also, the investigation revealed insufficient communication and collaboration between municipalities, their subordinated institutions, and families raising CWD, impeding the effective provision of the necessary services. Taking into account the results of the study, it is recommended to strengthen cooperation in the health, education and social sectors.

In summary, whilst legal regulations provide families raising children with disabilities with a range of support options, the accessibility of such services is limited. Therefore, extensive research involving parents on a large scale is required to better understand the limitations of the services available and accessible to families with CWD.

Limitations of the study

The limitations of this study highlight opportunities for future research. We conducted our research based on the perceptions of the heads of education, health, and social services departments of four municipalities and their subsidiaries. A manager's view of the availability of service may not align with the collective view, thus such subjective evaluations may not represent the views of other stakeholders. As the research has relied solely on the viewpoints of managers, however, it is suggested that future studies should include institutional leaders and service users, particularly parents of children with disabilities.

References

1. Akavickas, J. (2021). Tėvų, auginančių proto negalią turintį vaiką, santykių su sveikatos specialistais patirtis. *Health Sciences*, 31(3), 33-38. <https://doi.org/10.35988/sm-hs.2021.075>
2. Baranauskienė, I. (2021). Vaikų, turinčių negalią, diskriminacijos raiška Lietuvos sveikatos priežiūros sistemoje. *Specialusis ugdymas*. 1 (42), 99-115. <https://doi.org/10.15388/se.v1i42.593>
3. Bourke-Taylor, H., Lee, D. A., Tirlea, L., Tirlea, L., Morgan, P., & Haines, T. (2021). Interventions to Improve the Mental Health of Mothers of Children with a Disability: Systematic Review, Meta-analysis and Description of Interventions. *Journal of Autism and Developmental Disorders*, 51(10), 3690-3706. <https://doi.org/10.1007/s10803-020-04826-4>
4. Cantillon, B., Seeleib-Kaiser, M., & Van Der Veen, R. (2021). The COVID -19 crisis and policy responses by continental European welfare states. *Social Policy & Administration*, 55(2), 326-338. <https://doi.org/10.1111/spol.12715>
5. Chastang, J., Boussarsar, E., Chavannes, B., Bonello, K., Moussaoui, S., Skendi, M., Gomes, C., Cadwallader, J., & Ibañez, G. E. (2022). What are the factors associated with the quality of life for parents of children affected by neurodevelopmental disorders? Usage of the quality of life survey approved PAR-DD-QOL in general medicine. *Research Square*. <https://doi.org/10.21203/rs.3.rs-1501792/v1>
6. Dėl Lietuvos Respublikos sveikatos apsaugos ministerijos 2021 metų veiklos ataskaitos pateikimo. 2022 / Nr. (1.1.17-12) 10-1169. SAM.
7. Dėl Lietuvos sveikatos 2014-2025 metų programos patvirtinimo. 2014/Nr. XII-964. LRS.
8. Dėl medicininės reabilitacijos ir sanatorinio (antirecidyvinių) gydymo organizavimo. 2022 / Nr. V-1738. LRS.
9. Dėl šeimos medicinos plėtros 2016-2025 metų veiksmų plano patvirtinimo. 2016 / Nr. V-1104. LRS.
10. Dėl Socialinių paslaugų katalogo patvirtinimo. 2022/ Nr. A1-451. LRS.
11. Dėl vaikų raidos sutrikimų ankstyvosios reabilitacijos paslaugų teikimo ir jų išlaidų apmokėjimo tvarkos aprašo patvirtinimo, I priedas. 2018 / Nr. V-150. LRS.
12. Dėl 2021-2030 metų nacionalinio pažangos plano patvirtinimo. 2020 / Nr. 998. LRS.
13. Dizdarevic, A., Memisevic, H., Osmanovic, A., & Mujezinovic, A. (2020). Family quality of life: perceptions of parents of children with developmental disabilities in Bosnia and Herzegovina. *International Journal of Developmental Disabilities*, 68(3), 274-280. <https://doi.org/10.1080/20473869.2020.1756114>
14. Fu, W.; Li, R.; Zhang, Y.; Huang, K. (2023). Parenting Stress and Parenting Efficacy of Parents Having Children with Disabilities in China: The Role of Social Support. *Int. J. Environ. Res. Public Health* 2023, 20, 2133. <https://doi.org/10.3390/ijerph20032133>
15. Grigaitė, U. & Jurevičiūtė, G. (2020). Žmonių su negalia socialinės integracijos veiklos rezultatų bei jungtinių tautų neįgalųjų teisių konvencijos ir jos fakultatyvaus protokolo įgyvendinimo 2019 m. stebėsenos ataskaita. Prieiga per internetą: http://www.ndt.lt/wp-content/uploads/ZTSI_ataskaita_po_pastabu_FINAL.pdf
16. Hu, X. (2022). Chinese fathers of children with intellectual disabilities: their perceptions of the child, family functioning, and their own needs for emotional support. *International Journal of Developmental Disabilities*, 68(2), 147-155. <https://doi.org/10.1080/20473869.2020.1716565>
17. Huus, K., Olsson, L., Andersson, E. E., Granlund, M., & Augustine, L. (2017). Perceived needs among parents of children with a mild intellectual disability in Sweden. *Scandinavian Journal of Disability Research*, 19(4), 307-317. <https://doi.org/10.1080/15017419.2016.1167773>
18. Įtaukties švietime plėtros gairės. 2022. Švietimo, mokslo ir sporto ministerija.

19. Johansson, S., & Liljegren, A. (2020). Social service as glasshouses? On the use and consequences of the Open Comparison system in Swedish social services. *Financial Accountability and Management*, 37(3), 323-343. <https://doi.org/10.1111/faam.12277>
20. Lietuvos Respublikos socialinės apsaugos ir darbo ministerijos 2021 metų veiklos ataskaita. 2022 / Nr. D5-27 (1.2.1E). SOCMIN.
21. Lietuvos Respublikos sveikatos apsaugos ministerijos 2022 metų veiklos ataskaita. 2023. SAM.
22. Lietuvos Respublikos vaiko teisių apsaugos kontrolieriaus 2021 metų veiklos ataskaita. 2022. VTAKI.
23. 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. <https://doi.org/10.1080/23303131.2020.1734132>
24. Park, G., & Lee, O. N. (2022). The Moderating Effect of Social Support on Parental Stress and Depression in Mothers of Children with Disabilities. *Occupational Therapy International*, 2022, 1-8. <https://doi.org/10.1155/2022/5162954>
25. Piščalkienė, V., & Navickienė, L. (2019). Priemonių, skirtų negalia turinčių vaikų ir jų tėvų psichosocialinės sveikatos ir socialinės įtraukties gerinimui, poreikis ir nauda. *Health Sciences*. <https://doi.org/10.35988/sm-hs.2019.089>
26. Raudeliūnaitė, R., & Gudžinskienė, V. (2022). Tėvų patirtys ruošiantis vaikui, turinčiam autizmo spektro sutrikimą, lankyti pradinę bendrojo ugdymo mokyklą. *Pedagogika*, 147(3), 164-182. <https://doi.org/10.15823/p.2022.147.8>
27. Samsonienė, L., Malkin, M. B., Kairys, J., & Juozulynas, A. (2017). Šeimų, auginančių vaikus su autizmo spektro sutrikimu, gyvenimo gerovė. *Sveikatos Mokslai*. <https://doi.org/10.5200/sm-hs.2017.045>
28. Stefanidis, A., King-Sears, M. E., Gilic, L., & Strogilos, V. (2022). Work-family strain of employees with children with disabilities. *Equality, Diversity and Inclusion: An International Journal*, 42(1), 18-37. <https://doi.org/10.1108/EDI-02-2021-0039>
29. Staunton, E., Kehoe, C., & Sharkey, L. (2023). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*, 40(2), 192-199. <https://doi.org/10.1017/ipm.2020.4>
30. Savari, K., Naseri, M., Savari, Y. (2023). Evaluating the Role of Perceived Stress, Social Support, and Resilience in Predicting the Quality of Life among the Parents of Disabled Children, *International Journal of Disability, Development and Education*, 70:5, 644-658. <https://doi.org/10.1080/1034912X.2021.1901862>
31. Zhao, M., Fu, W., & Ai, J. (2021). The Mediating Role of Social Support in the Relationship Between Parenting Stress and Resilience Among Chinese Parents of Children with Disability. *Journal of Autism and Developmental Disorders*, 51(10), 3412-3422. <https://doi.org/10.1007/s10803-020-04806-8>

Laura Gardziulevičienė, Agota Giedrė Raišienė

PASLAUGŲ PRIEINAMUMAS TĖVAMS AUGINANTIEMS VAIKUS SU NEGALIA, REMIANTIS ALYTAUS REGIONO SOCIALINIŲ, SVEIKATOS IR ŠVIETIMO ĮSTAIGŲ VADOVŲ POŽIŪRIU

Anotacija. *Parama šeimai yra esminis komponentas įtakojantis tėvų auginančių vaikus su negalia dalyvavimą visuomeniniame gyvenime. Reikalingos paslaugos, kurios atitiktų tik vaiko išlaikymą, tiek tėvų gyvenimo kokybę, antraip valstybė netenka darbingų piliečių, kurie lieka atsakingi tik už vaiko su negalia auginimą. Tyrimo tikslas yra dvejopas: apžvelgti viešųjų paslaugų šeimoms, auginančioms vaikus su negalia, sistemą Lietuvoje ir išanalizuoti paslaugų prieinamumą paslaugas teikiančių įstaigų vadovų požiūri. Buvo atliktas struktūrinis interviu, kurio metu buvo surinkta informacija iš aštuoniolikos ekspertų, kurie yra savivaldybių ir pavaldžių įstaigų švietimo, sveikatos ir socialinių paslaugų skyrių vadovai, atsakingi už sprendimų priėmimą organizuojant ir teikiant paslaugas šeimoms, auginančioms vaikus su negalia Alytaus regione. Tyrimų duomenimis, Alytaus regionas turi potencialą teikti švietimo, sveikatos priežiūros ir sociali-*

nes paslaugas pagal teisės aktų nuostatas. Tačiau dabartinis paslaugų spektras nėra pakankamas praktikoje. Dauguma paslaugų vaikams su negalia yra prieinamos tik tėvų prašymu, o kai kurios paslaugos nėra prieinamos ir poreikis lieka nepatenkinamas dėl daugelio priežasčių. Remiantis tyrimo išvadomis, nepakankamas paslaugų teikimas Alytaus regione daugiausia susijęs su aptarnaujančio personalo trūkumu ir ribotais finansiniais ištekliais. Kartu tyrime pabrėžiamas lėtas savivaldybių ir joms pavaldžių subjektų reagavimas į bendravimą ir bendradarbiavimą tarpusavyje bei su tėvais auginančiais vaikus su negalia.

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