

# Accessibility of Health Care Services for People with Disabilities: Case of Lithuania

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**Abstract.** *The paper examines the legal regulation of patients' rights to quality healthcare in Lithuania and the accessibility of healthcare services for people with disabilities. As the number of people with disabilities in Lithuania is very high as every tenth inhabitant has disability, we can state that people with disabilities can be considered as a health disparity population, underrepresented and unseen in mainstream research studies on health care. The paper applies accessible research design that means that people with disabilities can fully participate in research on accessibility of health care services and contribute to advances in the health care system. Applied research methods – content analysis of legal regulation on patient rights and health services; state reports, other national and international documents; conducted ethnographic study and analysis of attitudes of people with disabilities, their relatives and specialists towards accessibility of health care services according different dimensions of accessibility – allowed to identify the barriers of access to health care services. The research brought to conclusion that the health care system in Lithuania needs changes; accessibility of health care services for people with disabilities is insufficient due to underfunding of the health care system, services are still not patient-oriented and do not meet their needs, obvious problems of discrimination and ethics; limited physical availability of health care services for people with disabilities; other problems also were identified. Knowing their needs will contribute to promote the accessibility of health services, avoid barriers to health care, improve the health of population in Lithuania, reduce disparities of health status, achieve social sustainability.*

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**Keywords:** *Accessibility, health care services, patients' rights, people with disabilities, health care barriers, social sustainability.*

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## 1 Introduction

The importance and novelty of the scientific problem presented in the article is primarily associated with a new approach to disability research. In the global health system, as in Lithuania, the human rights model is struggling to gain ground (Baranauskienė, 2021, p. 18. Deneger, 2016, p. 2). To paraphrase the authors, the social paradigm in disability studies is being replaced by the human rights paradigm and narrowing down the scientific problem – the implementation of the human rights model in the health system. The originality of the article is reinforced by the choice of ethnography as the epistemology of the study (Baranauskienė, 2021, pp. 27-34).

Health and universal availability of health care services have been indicated by World Health Organization (WHO) as an outcome, indicator and important driver of sustainable development. According to WHO, accessibility and patient orientation are important in health care quality aspects as well as safety and efficiency of services (WHO, 2006, pp. 9-10). Accessible health care services are those that are provided on time, within a geographically reasonable distance and where there are sufficient skills and resources. Access to health care impacts one's overall physical, social, and mental health status and quality of life.

Universal health coverage (UHC), central to better health and well-being for all, delivers gains across the 2030 Agenda for Sustainable Development, strengthens economic inclusion as well as health and human security (UNDP, 2019).

Sen (2015) highlights UHC as an “affordable dream” which countries of any income level can progress towards, however researchers note various barriers to access to health care services and underfunding of the health system remains among the most relevant ones. According to Mackey, Vian, & Kohler (2018), it undermines accessibility and equity, especially for people with different socioeconomic status, and in that way causes disparities of access to health care services. In addition, Manandhar, Hawkes, Buse, Nosrati, & Magar (2018) note that such a factor as disability can further exacerbate health disparities. People with disabilities are often at social risk, such as unemployment, poverty, lower education. It affects their health protection, access to health care services. “People with disabilities experience poorer health, greater incidence of chronic conditions, and higher health care expenditure than people without disabilities” (Rios, Magasi, Novak & Harniss, 2016). Moreover, Krahn, Walker, & Correa-De-Araujo (2015) state that people with disabilities can be considered as a health disparity population, underrepresented and unseen in mainstream research studies on health care.

Obrist, Iteba, Lengeler, Makemba, Mshana, Nathan R., et al (2007) defines access to health care, emphasizing the suitability, affordability, accessibility, adequacy and acceptability of care services. That has proven that the access to comprehensive, quality health care services is very important to promote and maintain health; to prevent and manage disease, to reduce unnecessary disability and premature death. Lithuania stands out with one of the lowest life expectancies, that is 75.8 years (2017), (EU average (80.9 years)), while the gender gap in life expectancy is almost double the EU average. Cardiovascular diseases, cancer are the leading causes of death in Lithuania. Share of population over age 65 in Lithuania is 19.3% (EU-19.4%) (OECD, 2019). More than half of Lithuanians aged 65 and over report having at least one chronic condition. These health problems in old age often result in disability. In such a small country as Lithuania with 2.7 mil. population the number of people with disabilities (PWD) is very high as every tenth inhabitant has disability.

Therefore, there is an undoubtable need to renew the state of knowledge in this area, as research of accessibility of health care services for people with disabilities contribute to the identification how the process meets UHC goals, embodies the pledge of the 2030 Agenda for Sustainable Development to leave no one behind; responds to WHO requirements to provide patient-centered services according to individual and societal expectations and priorities.

Paper is composed of a systematic overview of the legal framework and policy-making and analyzes the situation of access to personal healthcare services for people with disabilities in Lithuania. The article presents the authors' methodological approach, research ethics, analysis of the research results, and conclusions

## 2 Materials and Methods

A study of scientific works revealed that the experiences of people with disabilities, their relatives, and specialists working with them in the healthcare system have been little researched or researched only in certain aspects (for more details, see Baranauskienė, 2020, pp. 9–21). The results of the scientific study revealed that representatives of the social sciences, rather than the biomedical sciences, are more interested in this topic. In most cases, the studies presented are not interdisciplinary. Representatives of the social sciences most often explain the situation under study through the prism of the social model. The human rights model, as a theoretical concept, appears in the works of only a few scholars. Articles representing the biomedical field sometimes apply the clinical model (Baranauskienė, *ibid.*). It can be said that the research presented in this article has entered a field that has been little explored in Lithuania.

We performed content-analysis of national legal regulation of patients' rights to quality healthcare in Lithuania, qualitative analysis of narratives of persons with disabilities, their relatives and specialists. We supported the identification of the situation of health service accessibility for people with disabilities (hereinafter – PWD)

by analysing state reports, other national and international documents in this field. The paper applies accessible research design that means that PWD can fully participate in research on accessibility of health care services and contribute to advances in health care services.

*Methodological approach.* The research methodology is primarily associated with the logic of the research, research ethics, a detailed description of the research location and participants, the data collection method, and the disclosure of the data collection process: “(...) in other words, methodological complexity is used rather than methodological uniformity, with more attention paid to describing ways of cognition and their potential interaction. Interaction here is understood as an important practice in the social sciences, based on the concepts of dialogue, conversation, conflict, and intersubjective conventions” (Valantiejus, 2004, p. 60). Our primary research question, “What are the experiences of people with disabilities, their relatives, and specialists in the healthcare system?” leaves a lot of room for researchers to operate. The research data was collected by following the research participant (for more details, see Baranauskienė, 2021, pp. 25–41).

The article is based on the survey data received implementing the project “Researching specialist training to provide holistic help to people with disabilities in the health care system while improving researcher competencies” and presents a part of it. We found out that empirical studies are important because they focus on determining the barriers to accessibility. We chose the United Nations Convention on the Rights of Persons with Disabilities as a conceptual basis for the selection and analysis of research data and examined it in the context of the human rights model, which means that humanism, as an ongoing aspiration, must affect not only the personality itself, but also the personality must strive to preserve the humanity of the other person (Morkūnienė, 1995; Cibulskaitė, 2000). The authors of the article associate their scientific thinking with post-positivism in collecting research data, analyzing it and forming findings. Thus, from an ontological perspective, the findings of the study do not claim absolute truth. Both in developing the research strategy and in collecting and analyzing the data, we sought to look at the phenomenon from a variety of perspectives.

We delved into the opportunities provided by the health care system for people with disabilities from the positions of all participants in the system: people with disabilities (PWD), their relatives (R) and specialists (S). For that purpose, we chose interactive ethnography as a method to collect research data (Spradley, 1980; Spradley & McCurdy, 1972; Green & Harker, 1988; Green & Wallat, 1981; Castanheira, Crawford, Dixon, & Green, 2000; Skukauskaitė, 2017) as from the point of view of epistemology, we realized that the assessment of reality depends on many factors: the subjective attitude of the research participants, the subjective interpretations of the researcher, the context of the environment. On the other hand, interactive ethnography has been chosen as the methodological approach to data collection, which, although has clear methodological provisions, leaves enough space for flexibility for researchers’ decisions. An approach

to interactive ethnography requires a comprehensive analysis of the problem: from different perspectives, examining different experiences and discourses, taking into account all groups of individuals involved in the situation, as well as taking into account historical, social and cultural contexts.

Project authors organized up to 8 ethnographic interviews with 30 people with various disabilities, 30 of their relatives and up to 5 ethnographic interviews with 50 specialists (doctors, nurses, physiotherapists, social workers and others) providing care for people with disabilities using a life story method. The survey was conducted in different health care institutions throughout Lithuania, the time of data collection and recording: 14-03-2018 – 14-09-2018.

*Research ethics.* Ethical principles were observed both in introducing the research to the research participants, ensuring their anonymity, and in respecting the research participant as a person, considering his or her well-being and feelings (ethics in collecting data and interpreting it over the “content” of data).

The collection of research data was organized by abandoning the pre-construction and following the research participant, and, if possible, some research participants were met and called upon to understand the interpretation of the data to achieve their full reliability. Dialogue and conversation methods were used in data collection. Agreements between the project participants organizing the interviews, a memorandum, a research plan and training provided an overall research strategy and ensured a unified process.

Prior to start the study, an approval from the Bioethics Commission of the Department of Rehabilitation of Klaipėda University was obtained (protocol No. SV-RK-10). The documents of survey were presented to the Commission: the summary of survey; list of research participants (people with disabilities, their relatives, specialists); confidentiality agreement; framework agreement; agreement on interviews with people with disabilities and their relatives; agreement on interviews with health professionals (specialists) working with people with disabilities; participant consent form A (for persons with disabilities and their relatives); participant consent form B (for healthcare specialists). All research documents have been prepared for the research participants in accordance with generally accepted ethical principles.

### 3 Results

*Legal regulation of patients' rights to quality healthcare in Lithuania.* The analysis of the state legislation presupposes that main legal acts in Lithuania provide statements on general availability to health care services. The foundations of access to health care are enshrined in the Constitution of the Republic of Lithuania (1992): Article 53 stipulates that the state shall take care of human health and guarantee medical assistance and services in case of human illness; the concept of access to health care services is defined by the Law on the Health System of the Republic of Lithuania (1994); the legal norms regulating the provision of personal health care services are provided in the Civil Code

of the Republic of Lithuania. The Law of the Republic of Lithuania on the Rights of Patients and Compensation of the Damage to their Health (1996) provides for the right of patients to affordable health care and defined it as free health care and immediate emergency care; defines the concept of quality health care (2004); establishes the right of patients to quality health care services: the law stipulates that patient treatment and health care services in particular must be available and provided by the right specialist or their team at the right time and in the right place (2009). As Astromskė (2018) pointed out, the legislator clarifies the definition of the concepts of quality and accessibility of health care services, establishes these aspects of the functioning of the health system not only as a duty of the state in organizing health care, but also as a right of patients. Unfortunately, it is the only law in the Republic of Lithuania that mentions disability. It states that ‘the relationship between the patient and healthcare professionals and healthcare institutions is based on the following principles: “<...> the prohibition of restricting patients’ rights on grounds of sex, age, race, nationality, <...> disability or otherwise, except in cases provided for by law, without prejudice to the general principles of human rights” (Seimas of RL, 1996).

Other Lithuanian legal acts regulating health care do not provide statements for the availability of treatment for people with disabilities. However, the Law on the Health System of the Republic of Lithuania (1994) contains a provision on the general availability of such care: “the potential of health care and the conditions for its maintenance are determined by ... accessible, acceptable and appropriate health care”, and Article 34 provides that “equity of health care” means “state-recognized health care” conditions with equal access to health and to minimize disparities between those seeking it” (Seimas of RL, 1994).

The Parliament of the Republic of Lithuania (Seimas) in 2010 May, ratified the United Nations Convention on the Rights of Persons with Disabilities (2006) (further on – Convention).

Lithuania undertakes to ensure the implementation of the provisions of the Convention and to take appropriate measures to ensure that persons with disabilities have equal access to the physical environment, transport, information and communication, including information and communication technologies and systems, and other public facilities or services. These measures, which include the identification and removal of barriers and obstacles to access, shall apply, *inter alia*, to medical institutions.

However, the Law of the Republic of Lithuania on the Social Integration of People with Disabilities (1991, new wording from 2005-07-01) is very laconic about the availability of health care services for people with disabilities: Article 7 in first point states “In order to ensure equal rights of persons with disabilities in the field of personal health care, personal health care services for persons with disabilities shall be provided at the same level and under the same system as other members of society.”

Facilitating access to health care services a number of documents of legislation have been adopted to ensure access to health services in the shortest possible time. In



order to reduce the waiting time for health care services, the legislator in Lithuania first chose the means of applying responsibility to patients: a patient who has registered but is unable to arrive on time must inform the health care institution in advance (Law of the Republic of Lithuania on Patients' Rights and Compensation for Damage to Health supplemented by provision in 2015). Another measure reduces waiting time for health care services: in 2016 it was adopted and from 2018 January 1 Amendment to the Law on Health Care Institutions of the Republic of Lithuania came into force, establishing indicators for the evaluation of financial results and performance of health care institutions (Seimas of RL). It also sets the deadlines for patients to be provided with all levels of healthcare services. The preconditions for the adoption of new legal acts are influenced by the increasing coordination of the Lithuanian health system with the health policy of the European Union and the desire to ensure internationally recognized health care standards.

Lithuania's preparation for and accession to the OECD has given a new impetus to the adoption of more quality standards in health care services and to expand the list of indicators used to assess the quality of health care; to improve health of the population and reduce inequalities in access to quality health care (OECD, 2019). In 2017, the Minister of Health approved a program for improving the quality of personal health care services; plan of implementing measures in 2018-2020.

*Evidence based health care services accessibility for people with disabilities.* Health care services accessibility for people with disabilities was analyzed on the basis of the Convention on the Rights of Persons with Disabilities (2006) and broken down into sub-themes. We obtained six sub-themes in both the Convention and the survey: Accessibility of services; Universal design; Financial affordability; Ensuring a communication environment; Availability of information environment; Accessibility of the geographical environment. Though, Staff training on accessibility highlighted in the Convention, in the research of accessibility to health care services for people with disabilities was not found. The concept of Accessibility highlighted in the preamble is assessed in the context of our research as connecting all themes and chosen as a generalizing theme.

Following a thematic analysis of the study on accessibility to health care services for people with disabilities in Lithuania, 203 episodes related to a general concept of accessibility were selected. During the next stage of the thematic analysis delving into the semantic expression of the episodes and searching for potential sub-themes, we have broken them down according to semantic similarity, defining and naming sub-themes. Episodes in terms of semantic similarity "fell" into groups reflecting the expression of the theme Accessibility. The logic and results of the subtopic analysis are presented in Table 1.

**Table 1.**

*Results of the analysis of the accessibility theme.*

<b>Results of the thematic analysis of the CRPD on accessibility (sub-themes)</b>	<b>Results of the research of the thematic analysis of accessibility of the health care system for people with disabilities (objects of sub-themes)</b>
<b>Accessibility of services</b> (Preamble; Art. 8; 19)	<b>Accessibility of services</b> – 107 episodes Health care system itself reduces accessibility – 33 episodes Difficulties of access to psychological and psychiatric care – 22 episodes The need for mediation – 16 episodes Health care system itself forces to use a private medicine – 8 episodes Difficult to access dental care – 8 episodes “There is no room for such patients” – 7 episodes Unclear disability assessment procedure – 6 episodes Other factors that increase and decrease accessibility – 7 episodes
<b>Universal design</b> (Art. 2; Art. 4) Accessibility of the physical environment (Art. 8; Art. 25) Availability of aids and technologies (Art. 26).	<b>Universal design</b> – 29 episodes
<b>Financial affordability</b> (Art. 25; Art. 28)	<b>Financial affordability</b> - 23 episodes
<b>Ensuring a communication environment</b> (Art. 21) Ensuring the diversity of forms of communication	<b>Ensuring a communication environment</b> – 25 episodes Communication difficulties – 14 episodes Insufficient communication of doctors with patients reduces the availability of treatment – 11 episodes
<b>Availability of information environment</b> (Art. 8)	<b>Availability of information environment</b> – 10 episodes
<b>Accessibility of the geographical environment</b> (Art. 8; Art. 25; Art. 26)	<b>Accessibility of the geographical environment</b> – 9 episodes
<b>Staff training on availability</b> (Art. 8)	Undiscovered subtopic

We singled out the items that the best reflect the expression of the theme and named the sub-themes accordingly. 107 episodes have been selected to illustrate the attitudes of the research participants – people with disabilities, their relatives, practitioners/specialists – on accessibility of health service for disabled people to identify the barriers of system. It is important to note, that in this article we analyzed and presented results of the first theme Accessibility of services and the group of its eight main sub-themes: Health care system itself reduces availability (33 episodes); Difficulties of



access to psychological and psychiatric care (22 episodes); The need for mediation (16 episodes); Health care system itself forces to use a private medicine (8 episodes); Difficulties to access dental care (8 episodes); “There is no room for such patients” (7 episodes); Unclear disability assessment procedure (6 episodes); Other factors that increase and decrease accessibility (7 episodes).

The number of selected episodes that reflect the expression of the situation and the attitudes towards it, is more illustrative than semantic in the table, as we took a point of view that even a rarely recurring episode may be no less important in its sense than a recurring one. The illustrativeness and nuances of expression of the sub-themes are, in our view, more important than the integrity of the theme, consequently, in some cases emotional thinking overcomes a logic one.

Analysis of implementation of legal documents on accessibility of health care services, analysis of state and international documents of current health care situation in Lithuania and results obtained during the interactive ethnography research, allowed us to identify the main barriers to health services for people with disabilities. Knowing their needs would contribute to the promotion of the accessibility of health services, avoidance of barriers to health care, improvement of the health of population in Lithuania, reduction of disparities of health status, achievement of social sustainability.

#### 4 Discussion

The review of the development of legislation in Lithuania on accessibility of health care services shows the tendency to adjust definitions and concepts of universal health services. National legislation, establishing more detailed requirements at the state level, enabling greater universality, coordination and control of health care provision criteria is being prepared and enforced. However, the lawyers themselves emphasize that “disclosure of constituent elements comprising the definition of right quality of healthcare concept – the conditions and criteria – enables the entities interpreting and applying it to determine whether there is a breach of the patient’s right to high quality health care services. Violation of the right to high quality health care services is only possible due to the non-compliance of the criterion of the concept of high quality of health care delivery conditions” (Sriubas, 2013).

Key actors in ensuring accessible and patient-centered health care services in Lithuania are the Ministry of Health, the State Accreditation Health Care Service, the State Health Insurance Fund and about 1.2 thousand treatment institutions. Primary health care routinely acts as a first contact point with the health system for patients, is delivered in public or private health care centres by general practitioners (GPs), who play a gatekeeping function to more intensive levels of health care. Specialist outpatient care is delivered by the outpatient departments of hospitals or polyclinics, as well as by private providers. Unfortunately, health care system in Lithuania has shortcomings.

The analysis of the attitudes of the research participants – people with disabilities, their relatives, practitioners/specialists – on accessibility of health service for disabled people allowed us to identify the barriers of the system. As mentioned above, for the theme Accessibility of services (107 episodes) we identified eight main sub-themes and the elements that best reflect the expression of the sub-theme. In order to reveal the content of the sub-theme and better understand the situation, to create preconditions for the change of the situation, each sub-theme object has been analyzed separately. As can be seen, even each object illustrating the sub-theme has its own expression. Their analysis, the separation of essential features, allows to establish connections and to make generalizations.

#### *4.1 Health care system itself reduces accessibility*

We identified ten main elements of the sub-theme:

- *Work overload* (S3): how much time is needed for physiotherapy for each patient is decided by the family doctor (GP); the opinion of a specialist has no influence on the decision on the number of patients; quality of service suffers due to high work overloads.
- *Insufficient funding* (S9): the rates of the Health insurance fund for the services provided by health care institution are insufficient; due to insufficient funding, the managers of the institution refuse individual services, shorten the service provision time; the quality of service suffers; the specialists understand the manager, otherwise the institution would go bankrupt.
- *Poor working conditions* (S11): speech therapist is poorly equipped with work equipment; specialist buys equipment himself and has to bring the documents proving the purchase to the managers every time and hear the complaints that he buys too many tools; speech therapist often buys instruments from their income and it seems the norm to the manager; there is no transparent and consistent system of providing work equipment for the speech therapy room.
- *Hard to access health care services* (PWD12): the required health care service is available in a month or even in half a year; too short registration time to the specialist.
- *Seasonality* (S3): parents tend to take their children to the sanatorium during the warm season; sanatoriums and rehabilitation institutions accept too many patients during the warm season to survive the winter; the working conditions of a specialist and the quality of services are greatly influenced by seasonality.
- *Generic pharmaceuticals* (R24): because generic pharmaceuticals are not suitable, a doctor prescribes medications non-reimbursable by state for a person with schizophrenia and depression; doctor says that they are not the only ones, that he has many patients who have to buy non-reimbursable medicines; it is expensive when you also need to buy pharmaceuticals prescribed by another doctor for another reason; pharmaceuticals make up a large part of the family budget.

- *The family doctor does not visit the disabled person at home* (PWD17): a family doctor does not visit a person with a severe disability at home; it is too difficult for a person with disabilities to get to a health care center; person with disabilities communicates with the doctor by phone; prescription medicines are bought by a neighbor.
- *The system does not allow you to feel dignified* (PWD10): a person with a serious illness is provided with only minimal conditions for hygiene; even the shower is left on the initiative of relatives, like the change of environment, the opportunity to go outside; such situation violates the dignity of a person with oncological disease and his relatives.
- *Insufficient prevention* (PWD8): only prescriptions for medicines are issued to a person with a disability; a person would like the doctor to delve into the course of his illness in order to predict, recommend how to live with the illness.
- *Many aids are missing* (PWD4): assistive products for people with disabilities are ordered without delving into the situation, without achieving quality and individual needs (e.g. hearing aids at the lowest price).

Analysis of the studied narratives allow us to conclude that access to the health care services for people with disabilities is reduced by an insufficient health care system and situation can be changed only by systemic solutions. Though the Ministry of Health in formulating health care policy and organizing its implementation, takes measures to improve access to personal health care and patient orientation, however, the following shortcomings remain: ineffective measures to reduce service time waiting; e-health does not function properly; health care professionals' structural imbalances and other problems. Lithuania has among the highest mortality rates from preventable and treatable causes in the EU (OECD (2019)).

#### 4.2 Difficulties of access to psychological and psychiatric care

We singled out six elements describing the object of sub-theme.

- *Pharmaceutical treatment predominates* (PWD16) related with another item –
- *Alternative services not available* (PWD5): in the case of several diseases, different doctors prescribe their own medications from which the patient felt unwell; the situation improves when the medication was refused; complementary, alternative methods and supplementary medicine are not proposed
- *Unavailability of communication with psychologists and psychiatrists* (S34): The activities of psychologists and psychiatrists are focused only on diagnostics; almost no psychological consultations for people with disabilities at hospitals.
- *Long time waiting to psychiatrists* (R21): to get to the psychiatrist is possible in a few months.
- *Psychological help is not available*: people who have experienced psychological problems and crisis have nowhere to turn and do not receive appropriate psychological help. The only way – private psychological services for those who can afford them (R13).

- *The available psychiatric services are not of good quality (S34)*: people are isolated into psychiatric clinics; limited opportunities for outdoor walks.

Every single episode of the narratives reveals that in the case of a disability (not mental), the help of a psychologist, although much needed, is unavailable. The expression of the identified essential features make it possible to state that psychological help is difficult to access for people with disabilities. A study of many conversation episodes reveals that many people are dissatisfied with psychiatric care for a variety of reasons: poor treatment conditions, few staff, work overloads. All analyzed cases allow us to assume that in Lithuania psychological and psychiatric help is difficult to access for people with disabilities, both those with mental disabilities and those who are without them but find themselves in a crisis situation. The problem of psychological help is very serious, as suicide remains an important cause of death, particularly among men. Lithuania recorded the highest rate of mortality from this cause in the EU (OECD, 2019). At present, only people who can afford to pay themselves for the services provided by private psychologists, can receive psychological help, while others cannot. Available and timely psychological assistance to every Lithuanian citizen would help to maintain the psychological health of the society and contribute to the prevention of mental disorders.

#### **4.3 The need for mediation**

The analysis of the narratives allow us to single out four elements that describe the object of the sub-theme and also reveal the impact on the accessibility of the medical care system for people with disabilities.

- *Social workers as mediators (S17)*: the social worker's clients do not want to go to the doctor alone, they ask the social worker to accompany them; social worker has noticed that when she formally introduces herself to the treatment institution, things are handled more smoothly.
- *Total dependency on relatives (R15)*: a person without relatives would not be able to live independently; would not be able to go to the doctors.
- *There is no one to take care (S34)*: a person with a mental disability who returns home from the hospital does not receive support, stops taking medication and, when his health is deteriorating, returns to the hospital.
- *Lack of family support (R11)*: difficulties to balance work and nursing of a relative.

The common feature of all the studied cases is the need for mediation in the health care system. It can improve the accessibility of the system, and in its absence, the system moves away from a person with a disability.

#### **4.4 Health care system itself forces to use private medicine**

We singled out three elements that describe the object of the subtopic (out of 8 conversation episodes):

- *Private services must be chosen, due to unsuitable premises (PWD10)*: the main criterion for choosing a healthcare institution for a person with a physical disability is the institution he/she can enter; for this reason, only, private dental clinics are available.
- *It is difficult to get to specialists (PWD13)*: for half a year we have been trying to get a state-funded rheumatologist; a visit to a private specialist would cost at least 150 €.
- *Long waiting time for testing (PWD5)*: a person chooses non-state-reimbursed testing (examination) because the waiting time in public is half a year; feeling unwell does not allow them to wait.

The semantic expression of the element *Private services must be chosen*, due to unsuitable premises have direct links with the sub-theme *Universal Design*; the expression of the element *Long waiting time for testing* can be integrated into the element *Difficult to access specialists* (research is done by specialists). As has been mentioned above, such a division of elements, rather than integrity, is important for this study to reveal the specifics of the expression in order not only to better understand the situation, but also to focus on practical change. It is an analogous situation revealing the connection of the element with the sub-item Financial Affordability (unavailability).

Addressing the issue of health services availability, 17% of patients use paid services (half of them do so due to long time waiting), 19% – treat themselves (National Audit Office of Lithuania, 2017).

Physical accessibility to health care services for people with disabilities, suitable premises, special equipment in health care institutions still are insufficient in Lithuania, though already in 2001, an order on Construction Technical Regulation (CTR) was issued by Minister of the Environment of the LR. In 2017 the survey on Adaptation of the physical environment for people with disabilities at state and municipal health (treatment) institutions, ordered by Ministry of Social Affairs and Labor of the Republic of Lithuania was completed. The survey involved 340 out of 490 in operation health care (treatment) institutions. The analysis of the results of the survey shows that 30 percent of the surveyed health (treatment) institutions have parking spaces for people with disabilities equipped in accordance with all the requirements of the CTR; 68.8 percent of the institutions can be entered through the main entrance (the entrance is smooth, without thresholds or can be entered by a built-in external (outdoor) ramp or by elevator; 3.5 percent of the institutions have equipped side entrance marked with direction signs, 8.5 percent – unmarked; 19.1 percent of the institutions indicated that access to the building was not possible for people with disabilities. 74.7% of the institutions are not adapted for people with vision impairments; 63% of the institutions do not have reception facilities adapted to the needs of people with disabilities. There are sanitary facilities adapted to the needs of people with disabilities in 13.5 percent of the institutions (toilet(s), shower(s) and bath in every floor of building), but as much as 36.5 percent of the health care institutions do not have toilets, 3 percent – showers/baths adapted to the needs of people with disabilities. 66 percent of the health

(treatment) institutions do not have rooms (wards) adapted for people in wheelchairs and do not provide inpatient services. 31.7 percent of the health (medical) institutions do not have the medical equipment for people with disabilities (gynecological chairs, dentist's and other diagnostic equipment). This situation violates health care service accessibility, though it is gratifying that 70 percent of the respondents answered that even if the medical equipment is not adapted for a person with a disability, he/she will still be provided with this service. The analysis of the results of the survey shows that physical availability of health care services for people with disabilities in public institutions is very limited. Situation is much better in private health care institutions, but this issue requires a special survey. Though national insurance fund provides sign language interpreters and assistants for patients who are deaf and blind, however, centers for sign language interpreters are only located in the biggest cities, consequently, accessibility in rural areas is limited.

#### ***4.5 Difficult to access dental care***

We singled out four elements describing the object of the sub-theme:

- *The paid service is chosen* (R1): due to unavailability of state funded dental care services, the caregiver chose private services for her patient.
- *Unavailable assistance to a person due to disability and age* (R25): visually impaired person does not have access to dental care for financial reasons, and this affects quality of life (grated food is produced on a regular basis).
- *Dental care unavailable due to abuse of primary care center* (R4): the primary health care center does not provide access to free dental care for a mentally disabled person, although the state provides funding for it; provided services are of insufficient quality for people with disabilities.
- *Long service waiting time* (R2): in a disability situation, the provision of dental care is often complicated due to the specifics of the disability.

All of the above presented elements prove that dental care is difficult to access for people with disabilities. Further, disabled patients with behavioral disorders are not able to use regular dentist services and are therefore sent for treatment with general anesthesia. Few institutions provide dental treatment with anesthesia as day surgery, as required by existing legal regulation, leading to limited availability of services; coverage is very limited of pharmaceuticals – 33% and dental care just 18% in Lithuania, which hampers accessibility of service (OECD, 2019).

#### ***4.6 There is no room for such patients***

The analysis of the narratives of doctors, other specialists, people with disabilities, and their relatives allowed us to suggest that the expression of the sub-theme is revealed by four elements:



- *Not admitted to hospital after emergency* (R25): if a person with a disability is old, he or she is given first aid but is no longer treated.
- *“Go to another hospital”* (S33): the medical institution is not adapted to perform the examination that is necessary for a disabled person. The head of institution advises the doctor to recommend the relatives of the disabled person to go to private institution.
- *Outdated things are not treated* (S30): patients from the nursing hospital are examined at admission and they are sent back to the nursing hospital but not treated.
- *The wishes of the person are not considered* (PWD17): a person who complains of heartache is taken to an infectious hospital against his will; a person is discharged from an infectious hospital home at his own request.

From the context and the ironic narrative, it can be concluded that the doctor would like to help a patient brought from a nursing hospital, but the system does not allow this. There are no signs of help in the semantics of the narrative, therefore, the element is named as Outdated. The expression of the element of the object “go to another hospital” is related to the theme of Universal design, as many public health care institutions do not have treatment facilities adapted for people with disabilities, unlike private ones. From the theme Universal design, the sub-theme object element “go to another hospital” differs in semantic approach: let them drive for private testing (Sg33) – there is no place for a person with a disability in a public medical institution; wishes of the person are not considered (S30). Analysis of the narratives proves that health care services are still not patient-oriented and do not meet their needs, there are obvious problems of discrimination and ethics. The situation is quite serious, as more than a half of Lithuanians aged 65 and over have at least one chronic disease (OECD, 2019). The review of all above analyzed issues allows us to conclude that they are also related to the sub-theme Universal design.

#### 4.7 Unclear disability assessment procedure

We identified two main interrelated elements that characterize the sub-theme that are very similar:

- *Referral from specialist to specialist* (PWD9): a person complains about the situation when half a year after the diagnosis of disability he is sent to specialists to confirm the diagnosis and must waste time waiting to get to the doctor.
- *Bureaucratic process* (PWD9): according to the person, when he visits the doctor to confirm disability, the doctor does not go into the person’s health problems, but only fills in the documents; the person feels that he has not been to the doctor, but to the administrator.

It can be summarized that the elements *Referral to specialists*, *Bureaucratic process* reveals the expression of the object *Unclear disability assessment procedure* and confirms that the Disability assessment system requires changes, both in the procedure itself

and in the aspects of the best possible treatment as a service. Disability in Lithuania is assessed by Disability and Working Capacity Assessment Service under the Ministry of Social Security and Labor. Analyzed narratives allow us to note that information on this issue for people with disabilities is insufficient, sometimes incomprehensible.

#### ***4.8 Other factors are increasing and decreasing accessibility***

In seven narratives we identified three elements characterizing the sub-theme:

- *Shadow Economy* (PWD6): out-of-pocket payments for sensitive private services in public health care institutions remain relevant; it increases health care services accessibility (PWD9).
- *The Right Doctor* (PWD9): finding “your” doctor ensures that you can get help in time.
- *Mess* (PWD9): due to weak e-health system, often a paper health story of the patient is missing.

After examining the object of the sub-theme, it can be stated that its elements *Shadow Economy*, *Right Doctor* and *Mess* are united by the essential feature – accessibility. Informally purchased service, finding the right doctor, can increase the availability of services, while the absence of a basic procedure – a mess – can reduce it. This sub-theme is related to financial affordability. Private health care services are expensive in Lithuania, and only wealthy people can afford them. Lithuania’s spending on health care accounted for 6.5% of GDP in 2017 is among the lowest in the EU (average of 9.8 %). In addition, only two-thirds of current health expenditure is publicly financed (67%, compared with 79% in the EU). Underfunding of the health system undermines accessibility and equity, though a single health insurance fund provides care to nearly the entire population (OECD, 2019).

## **5 Conclusion**

In national legislation we observed a trend to adjust the definitions both of the concepts of quality and accessibility of health care services establishing more detailed requirements at the state level, enabling greater universality, coordination and control of health care provision criteria due to increasing coordination of the Lithuanian health system with the EU health policy and the aim of ensuring internationally recognized healthcare provision standard is being prepared and enforced.

Analysis of the research results allowed us to highlight the main problems of accessibility of health care services for people with disabilities and identify barriers: underfunding of the health system undermines accessibility and equity, violates human dignity. Health-care services are still not patient-oriented and do not meet their needs, there are obvious problems of discrimination and ethics. Measures for health prevention are insufficient and pharmaceutical treatment dominates. Physical availability of health

care services for people with disabilities in public institutions is very limited and that hampers service accessibility. There is a great lack of psychological services for people with disabilities.

A health care system itself needs systemic change. Ministry of Health in formulating health care policy and organizing its implementation, takes measures to improve access to personal health care and patient orientation, but the following shortcomings remain: ineffective measures to reduce service time waiting; e-health does not function properly; health care professionals' structural imbalances and other problems impair access to health services.

### Author Contributions

**Leta Dromantienė:** conceptualization, data curation, methodology, writing – original draft preparation.

**Ingrida Baranauskienė:** conceptualization, formal analysis, resources.

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