# LITHUANIAN SOCIAL RESEARCH CENTRE VILNIUS UNIVERSITY

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# PHENOMENOLOGICAL ANALYSIS OF THE LIFEWORLD OF PERSONS WITH MOTOR DISABILITY

Summary of doctoral dissertation

Social science, Sociology (05 S)

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The dissertation is available at the libraries of Vilnius University and Lithuanian Social Research Centre.

# LIETUVOS SOCIALINIŲ TYRIMŲ CENTRAS VILNIAUS UNIVERSITETAS

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#### INTRODUCTION

Relevance and Problem of Research. Since ancient times people have been regarded as disabled not because of exclusiveness of their needs or extent of disability, but mainly because the greatest attention has been paid precisely on their weaknesses, unique characteristics. Thus, it has been emphasized, how they differ from others, and it has been completely ignored, what they have in common (Gudonis, Novogrodskienė 2000). The aforementioned view towards disabled ones has remained till nowadays. Persons with motor disability distinguish by their external characteristics, which do not meet a "normal" or "standard" image of man, therefore, they become a particularly distinctive social group, which by the rest members of society is usually perceived and evaluated as belonging to the group of "them", i.e., the group of different, strange, unfamiliar and avoidable people. The reason of it is a different "abnormal" physical appearance and sitting in a wheelchair. Social distance, existing between these people and other society members, disturbs the integration process of people with disabilities. Negative attitude towards disabled ones results in barriers to get into social, cultural, political and economic life of society and to become a full-fledged part of it.

According to the data of social report (2010: 149) of Ministry of Social Security and Labour, in Lithuania lived 269 033 disabled people, which constituted about 7,5 percent of Lithuanian residents in 2009, a quarter of them had a motor disability (Tretjakova 2006: 138). The growth trend of number of people with disability remains each year, although being insignificant. The number of persons with motor disability, especially of those, who have experienced spinal cord injuries, increases as well. Moreover, many people become disabled being of working-age and relatively a small number of them come back into the labour market, remaining economically inactive members of society. The efficiency of vocational rehabilitation programs, designed for disabled ones and implemented in the country, is reduced by insufficient adaptation of working places and public environment for persons in a wheelchair (Gruževskis 2008: 90; 130).

Therefore, there is an increasing need to research and analyze the mentioned social phenomenon, which is so heterogeneous and multidimensional that the issue of definition of disability concepts is a fundamental problem of sociology of disability so

far (Abberley 2002: 79). There is still a dispute of opposing theoretical perspectives, explaining, which concept of disability is more accurate theoretically, closer to the reality of this phenomenon. The tendency to break away from the traditional - biomedical and social – disability models and to look for new theoretical approaches, the axis of which would be the main subject of this phenomenon – a person with disability, is also noticed. It is little known, what social reality does he/she face, when sit in a wheelchair after an accident? What is disability, what is its importance and role in the life of person, who has been moving with a wheelchair since a childhood? How do these people go through the imposed social status of disabled and a social reality in general? More importantly, the majority of society knowledge about people with disability has is not received from disabled ones; it is just the opinion of society about them (Šeporaitytė, Tereškinas 2007: 20). Therefore, it is very important to hear, how disabled people perceive and experience the disability and their social reality.

Research, based on a positivist paradigm, is not able to disclose a subjective reality of disability, which is expressed through internal experiences of subjects, acting within the mentioned reality. Alfred Schütz, the pioneer of phenomenological sociology, argues that in order to be able to understand and analyze the social world scientifically, it is necessary to look back to social actors, for whom this world exists and where they are acting and experiencing subjects, bound with each other by various social relations and attributing specific, subjective meanings for those relations and experienced reality (Schutz 1967: 10). Alfred Schütz analyses the social world using phenomenological concept of *lifeworld*. After adjusting the concept in the social and pragmatic way he adapts it in interpretative sociology. Thus, following phenomenological perspective of A. Schütz, sociology must focus not on the social structures (social institutions, classes, etc.), but on the *lifeworld* of subjects, experiencing everyday (Overgaard & Zahavi 2009: 15). This is a world of everyday life, experienced by ordinary social actors intersubjectively, i.e., similarly or commonly, where subjects follow a natural attitude that directly experienced social reality is actually objective and all matters therein are seen as a matter of course and non - questionable.

Thus, A. Schütz's sociological phenomenology, which considers social actors as active creators of sense, rather than the recipients of externally and objectively defined meanings, helps to show, how disabled people perceive and interpret disability and

related facts and phenomena of their life, experienced during social situations and interactions.

The *lifeworld* of people with motor disability is unique and different from other socially significant groups by the fact that it is pierced by common, in other words, intersubjective, experience of physical disability, which is the central axis of the whole analysis of lifeworld of these people. In case of motor disability, since childhood a body has been characterized by features, which are different from a man, able to walk, or during later stage of life experiences certain modifications due to illness or injury, which cause the change of senses, possibilities and circumstances of moving in environment as well as the relation of corporeal subject with the world.

According to phenomenological tradition, the relation of body with the world is saturated with meaning from the very beginning, since the world for corporeal subject is the lived world, important world (Sadala, Adorno 2002: 286). Therefore, this research aims to show, how the researched ones, using narrations (during in-depth interviews), create and construct the significant social reality by subjective meanings, how they give meaning to their relationship with the world, what meanings they attribute to it, living and perceiving the mentioned reality through a disabled body.

Thus, the **scientific research problem** of dissertation is comprised of the following essential question: what is a subjective social reality of persons with motor disability, revealed, using Alfred Schütz's phenomenological concept of *lifeworld*?

**Subject of Research** – the *lifeworld* of persons with motor disability.

**Objective of Research** – to analyze the social reality, experienced and perceived intersubjectively by persons, moving with a wheelchair, following the theoretical perspective of phenomenological sociology, going into the main phenomenological topics of lifeworld: relationship with disabled body, lived space and time, and significant, the closest and anonymous social environment of non-disabled ones or institutionalized social environment.

## Tasks of Research:

- 1. To define theoretical models of concept of disability, their contradiction issues and trends of change in sociological discourse.
- 2. To explore the concept of lifeworld of Alfred Schütz, following which the social reality is analyzed in phenomenological sociology.
- 3. On the basis of empirical phenomenological research to reconstruct the lifeworld of persons with motor disability as intersubjectively experienced and their social reality, perceived, following a natural attitude.
- 4. To highlight the specific characteristics of living with congenital/childhood and later acquired motor disability, including subjective experiences of disabled persons' relationship with their body, its disability and a permanent movement tool a wheelchair, the peculiarities of lived space and time as well as social interactions with non-disabled society members.

### Theses to be defended in the dissertation

On the basis of research completed the following statements are defended:

- By differently lived and interpreted experience of disability the persons with motor disability can be typified into two distinct types: disabled since childhood and those, who become disabled at a later stage of life.
  - Persons, disabled since childhood, face the disability only during secondary socialization, after internalization of social typifications of disabled body of negative meaning, the overcoming of which and successful socialization requires the involvement into new social group or community, i.e., into a positive social structure, confirming their identity.
  - A disability, which is experienced by person at a later stage of life, acquires the meaning of a turning point in biography, since leaves a trace not only in his/her body, but also changes the identity and the whole subjective social reality, which needs a new sense structure, allowing the occurrence of individual resocialization.
- 2. Motor disability as a body phenomenon, lived intersubjectively, evidences by internal inconsistency between the active self and the part of own physical body,

- which became passive. Disability actualizes in the mind of disabled person through his/her corporeal relationship with the surrounding world and the presence of physically unavailable, inaccessible objects.
- Acquired motor disability causes the changes of lived time of disabled person, which evidence by the slowdown of subjective time flow, new (negative or positive) senses, attributed to the time lived with disability and its usage.
- 4. Disabled, moving with a wheelchair, experience and perceive the lifeworld spatiality in particular through living the (in)consistency between their body status and physical environment. Thus, from their point of view, the spaces of our country are still poorly adapted for rolling with a wheelchair.
- 5. Physically disabled people face with the dominant social knowledge about them, based on typifications, which do not meet with the image of their lived reality. This knowledge facilitates the manifestation of social power of non disabled members of society by creating and maintaining unequal relations with persons with motor disability during social interactions.

## **Methodologies of Research**

Research methodology is based on phenomenological sociology of A. Schütz. However, it cannot be attributed to the phenomenological sociology study in strict sense, since it is directed not so much towards the ways, by which social actors – persons with motor disability – constitute the lived social reality in subjective mind, following the natural attitude, as towards the senses and content, attributed to the lived experiences of those persons, related with disabled body and functioning with this body in social world.

Furthermore, the analysis is extended by the insights of Alfred Schütz's followers Thomas Luckmann and Peter Berger, connecting the phenomenological perspective of A. Schütz and symbolic interaction perspective of George Herbert Mead, adapting them for the analysis of (re-) socialization, acquisition/loss of social roles, identity of disabled persons, as well as by ideas of other phenomenologists Maurice Merleau-Ponty, Edmund Husserl, Lithuanian phenomenologists Dalius Jonkus and Donatas Večerskis about the relation of embodied subject with the world and his/her body, and by the insights of other sociologists. However, all of them are united by common provision that the

subjective experience of social actors, rather than "objective" actual content is the decisive factor, following which they define their situation in the world.

The following methods were used for dissertation research: scientific literature analysis and synthesis, unstructured in-depth interviews, qualitative content analysis and interpretative analysis of text data.

# **Scientific Originality of Research**

Motor disability is not the phenomenon widely analyzed by Lithuanian sociologists. Its individual aspects have been researched sociologically by Jolanta Pivorienė (1998, 2001, 2003), Jonas Ruškus (1997, 2002) Rūta Adomaitienė (1999, 2007) with Jūratė Mikelkevičiūtė (2001), Deimantė Šeporaitytė (2006) with Artūras Tereškinas (2006a, 2008), Anelė Vosyliūtė (2009) and other. Usually the research of persons with motor disability as of individual social group is carried out in the field of social welfare (Ruškus, Mažeikis 2007, Ruškus, Blinsturbas, Žukauskas, Daugėla 2006; Ruškus, Daugėla, Žukauskas, Blinstrubas, Šaparnis 2007; Ruškus, Daugėla, Žukauskas, Blinstrubas, Šaparnis 2007a), social education and rehabilitation (Skučas 2003, 2003a, 2006, Ostasevičienė 2002, Stomienė 2000) and while analyzing the issues of inclusion to labour market (Daugėla 2004, Miliauskaitė 2004, Gailienė 2006, Vinikaitytė 2007).

The reality of social life of disabled people in phenomenological perspective has not yet been researched in Lithuania. The present research is significant scientifically in that it draws attention on the everyday experiences of life with motor disability, which are analyzed, following the methodological guidelines of A. Schütz's phenomenological sociology. Thus, the social situation of physically disabled persons and the attitude towards the phenomenon of disability itself are shown from the subjective perspective of those, who experience it. Consequently, this research, showing the attitude of subjective, more precisely – intersubjective, disabled ones towards the reality of their life with disability, deepens the sociological awareness of those members of society.

What is more, the phenomenological analysis of the lifeworld shows a diverse world view, perceived by physically disabled persons, which is constructed from their reflected experiences, rendered in the way of narration. The research revealed the relation of disabled person with his/her body, as well as with external world through disabled body; the problems of his/her identity transformation, acquired or realized

during socialization in the face of disability, which is related with the influence of social environment, significant for the disabled one; different experience and perception of phenomenon of disability itself, when it has been lived with it since childhood or later stage of life. Finally, the unique space-time perception of lifeworld of disabled persons from the perspective of moving with a wheelchair and the social interaction with non disabled members of society, reflected by disabled themselves, is disclosed.

The life situation of disabled persons, moving with a wheelchair, is unique both socially and culturally, and differs from the experience of Western countries, since its essence is defined by specific national mentality and unique historical evolution (Ruškus 2002: 15), therefore, the present research is appropriate and valuable contribution to the development of scientific knowledge, regarding the social reality of persons with motor disability in the context of Lithuanian society.

## **Structure of the dissertation**

The dissertation consists of four main parts, as well as the Conclusions, References, and Annex 2 presented at the end of the thesis.

The first part of the thesis under the title "THE CONCEPT OF DISABILITY IN THE SOCIOLOGICAL DISCOURSE" is divided into four chapters:

1. "The prehistory of the occurrence of different disability concepts". This section presents the development of the sociological analysis of the disability phenomenon, starting with the functionalistic trend that had been prevailing in medical sociology during the first half of the 20<sup>th</sup> century. According to the theory of the role of a disabled person developed by Talcott Parsons (1951), as well as the "biomedical" approach to a physical impairment, this sociological analysis of the disability phenomenon had been forming the functionalist-biomedical concept of the impairment of the body defined by the degree of deviation from the fixed bio-physiological and, accordingly, the deviation from the social norms.

In the 60s, the functionalistic-biomedical perspective towards disability presented in medical sociology received a significant criticism, which facilitated the development of the opposite interpretative trend. Its originators are Erving Goffman (1963), with his theory of stigma, as well as American sociologists L. Anselm G. Strauss, Barney Glasser (1975), and British sociologist Mildred Blaxter (1975), who performed the research of

the experiences connected with disabilities and chronic illnesses, as well as the investigation for the search of their meaning. The works of this interpretative trend were pointed at the subjective experience of an individual illness or disability, as well as the meanings attributed to the interactions between the people with such an illness or disability and a society, rather than at their illness as an impairment and operational constraint. However, due to the lack of their practical applicability, the disability studies of the interpretative trend were rapidly overshadowed by the raise of the movement of people with disabilities for their social rights, which has gained a strong intellectual expression and with the help of a new course of the disability studies witnessed in the academic discourse of the Great Britain contributed to the formulation of the concept of social disability, which challenged the prevailing biomedical concept.

2. "The dichotomy of the models of disability concept". This section presents an opposition of the biomedical and social concepts of disability, and the theoretical paradigms forming the basis for these concepts, as well as the mutual interdependency of these models of concepts. The biomedical model of disability concept has gained its specific expression with the help of the initiative created in 1980 by medical sociologist Michael Bury and due to the International Classification of Impairment, Disabilities and Handicapping (ICIDH) published by the World Health Organization. In principle the disability here is equated to the impairment – the deviation from "normal" functioning of the body, which in turn prevents the traditional social roles. Consequently, the biomedical concept is based on the *paradigm of positivism*, which treats disability as the external and neutral fact; the objectively detected empirical reality, according to which the fact of disability is stated, is the bio-physical impairment of the body.

At first, the social model of disability occurred as some kind of criticism for the biomedical model and aimed at destroying the biological reductionism of the latter – the assertion that the physical body is a direct cause of disability. The social model is based on the paradigm of social constructionism, which tries to provide the reasoned social origins of the phenomenon of disability, claiming that people became disabled not due to the affection in their body, but due to the society that creates a variety of structural and social barriers, which take away the possibility to fully participate in social activities. As a result, disability occurs due to the social structure that limits an individual's functioning in a society. In other words, it is socially created and produced.

- 3. "The criticism for the concept of the social model of disability". Here all the attention is directed towards the shortcomings of the concept of the social model of disability, which hinder the strengthening and development of a theoretical side of this concept. Since in the biomedical concept, impairment and disability are connected by the close causal link, the creators of the social model, revealing a strong opposition to the biomedical concept, remove the body impairment from the mentioned cause-result relationship changing it by a social structure (Cole 2007: 169). Thus, in the social model of disability, an analytical distinction is created between the concepts of impairment and disability. Impairment here is reduced to the biological, while disability is attributed to the social field (Corker and Shakespeare, 2002; 3). Such a strict distinction between the concepts of impairment and disability forms the "embodied" concept of disability. While defining the impairment solely on biological terms, the social model of disability denies its social nature, which means that the body loses its social value and is separated from the individual self (Hughes, 2002: 67). Instead of developing the sociology course of motor disability the sociology of disability, together with the social model of disability and impairment, comes to the theoretical dead-end in the face of this dualism because the disabled human body is evaluated through the prism of biomedicine and its social life is politicized (Hughes and Paterson 2006: 1997). However, despite this interaction, in terms of the dichotomy relationship, the biological and social areas after all are intertwined (Imrie 2004: 288). In practical daily life, it is actually very difficult to determine the end of impairment and the beginning of disability, or the beginning of physical impairment and the beginning of the impact of social barriers on disability. It is therefore appropriate to look for the ways to speak about disability, its nature, avoiding the examination of the dichotomy of the discussed perspectives and the integration of different aspects of the phenomenon of disability.
- 4. "The theoretical approaches seeking to overcome the contradiction of the concepts of disability". This chapter presents the tendencies of medical sociology and disability studies to mitigate or even to overcome the contradiction created by the different concepts of disability. The biomedical model seeks to find the theoretical access to the enhancing the meaning of the social context of disability avoiding the biological reductionism. This is done through the concept of the bio-psychosocial model of disability and a theoretical perspective of the critical realism, which, nevertheless, are

not able to combine these contrary notions of disability. The theorists of social model seek to restore the significance of the corporeality aspect for the concept of disability providing physical impairment with social meaning. The examinations of the latter one often are based on the ideas of poststructuralism; however, it leaves no theoretical space for the examination of a sick, disabled body as a subjective, living and suffering being, inseparable from real feelings and actions of human beings embodied in time and space (Williams, Bendelow 1998: 209).

Thus, this paper discloses one of the possible solutions of overcoming or at least of mitigating the contradiction caused by the traditional models of disability concept, i.e. "embodiment" of the social model, extending it by the phenomenological concept of disability. According to it, disability is considered from the perspective of the embodied social actor, who experience disability every day as his/her distinctive corporeal presence in the world, as well as the outcome of the interrelation between him/her and his/her environmental, and social structures.

The second theoretical part of the thesis "THE LIFEWORLD IN TERMS OF THE PHENOMENOLOGICAL SOCIOLOGY BY A. SCHÜTZ" is divided into three chapters:

1. "The origins of the phenomenological analysis of the lifeworld in sociology." The central phenomenological concept of the lifeworld was taken by Alfred Schütz from Edmund Husserl, the pioneer of this philosophical trend. He turned the philosophical exploration of the lifeworld into a sociological project by uniting E. Husserl's phenomenology with Max Weber's interpretative sociology (*verstehende Soziologie*); thus, becoming a pioneer of the phenomenological sociology.

Therefore, in analysing the concepts of a subjectively meaningful action, subjective and objective interpretations, and understanding from the positions of the motivated actor and observer, A. Schütz sought to deepen and develop the interpretative ideas of M. Weber's sociology. However, he was doing this by creating a new trend of the phenomenological sociology taking the insights of the phenomenological philosophy as a basis for it. The most important theory of this trend, i.e. the lifeworld, was developed by A. Schütz by adopting the underlying ideas of E. Husserl's phenomenology of the lifeworld.

2. "The lifeworld as the world of daily life of natural attitude." The chapter consists of three sub-chapters. It is intended to discuss the directions of the development of the lifeworld analysis presented by A. Schütz's. He examines the world of daily life, or the world of work, where with the help of usual and routine ways social actors are constantly involved in the realization of their practical interests. Moreover, A. Schütz also details the pragmatic way of thinking of the lifeworld as a cognitive style, or the so-called natural attitude, to which he pays a considerable attention.

The concept of natural attitude is used by A. Schütz when determining the state of consciousness of an individual living in the reality of daily life, which manifests itself in the form of the uncritical belief in the integrity of the world the way it is seen and experienced (2.2.1.). A detailed analysis of this perception and interpretation of the world according to the natural attitude enables A. Schütz to use one of his key and underlying terms of the entire theoretical analysis, i.e. the *stock of knowledge at hand*. According to A. Schütz, this stock of knowledge at hand is used by an individual during every moment of his/her daily life, and it serves as a scheme for the interpretation of the things from the past, present and the expected future experience, which is always at hand in every situation. Thus, as stated by A. Schütz, the understanding of the lifeworld, as well as the interpretation of its social and cultural events, takes place in every moment of our life through the stock of knowledge at hand, which forms a typified character of the thinking in natural attitude.

A further analysis of A. Schütz's lifeworld focuses on the interaction between the individual efforts to understand the surrounding social world and the pre-imposed cognitive structure of this world (Wagner 1970: 16). For this purpose, A. Schütz uses the concept of the *relative-natural view of the world* presented by Max Scheler, which can also be characterized by the features of the natural attitude observable in the thinking of the subjects of the lifeworld (2.2.2.). This is a socially objectified system of the typifications concerning the lifeworld transferred by the main social group of an individual, which especially flourishes in a native language as a system of symbols (Schutz and Luckmann 1974: 94). However, it is important to stress that in contrast to E. Durkheim's 'social facts', it does not influence an individual with an external power. An individual accepts, interprets, modifies and redefines this system by giving it a distinctive, personal touch and significance (Wagner 1970: 17).

A subject of the lifeworld is seen by A. Schütz not as an individual, living in the isolated situations, but as the one constantly involved in the process of the direct experience, within which he/she develops or ages in the sense of maturity rather than in the sense of biological time. Therefore, finding himself/herself in the same situation, a social actor is experiencing it differently than before, as at that moment he/she has a broader and richer stock of knowledge at hand, which changes the anticipation and expectations connected with a situation, as well as his/her particular behaviours (Wagner 1973: 65). A. Schütz refers to this important and subjectively historical factor of each situation as the *biographically determined situation* (2.2.3.). To say that the situation is biographically defined, is to assert that it has its own history, which is the sedimentation of all the previous individual experiences that have turned into the *stock of knowledge at hand*; moreover, it is unique to each individual person (Schutz, 1970: 73).

3. "The intersubjective character of the lifeworld." This chapter encompasses four subchapters, which deal with the intersubjectivity of the lifeworld, which A. Schütz considers a preconceived condition for the direct human experience in the lifeworld. According to him, ever since its beginning the social world is intersubjective in several meanings: first of all, it is a place where I am confronted with the other and, secondly, it is the scene of my actions directed towards my consociates or fellow-men (Natanson 1970: 103). Thus, to live in the lifeworld of daily life actually means to live indulged in a wide range of social interactions with a number of different people, and to be intertwined in the complex network of social relationships (Wagner 1970: 30), which encompasses not only the current residents, but also predecessors and successors.

The reference for the analysis of the intersubjective world lies in the *Werelationship* (2.3.1.). This is the relationship of direct experience, into which one enters directly confronting his/her fellowman in the same space and time. The experience of *we-relationship* is primordial, as it is acquired not via the theoretical justification, but via the experienced confrontation with another man existing in the same world.

The other almost the most important cognitive aspect of the intersubjectivity is the mutual understanding. The *We-relationship* is exceptional and unique in that it helps people to perceive one another as unique individualities (Gurwitsch 1975: XXIV). Moving from the *We-relationship* between fellowmen to the relationship between contemporaries, the radical change occurs in the other level of understanding (2.3.2.); an

individual knows his/her contemporaries via typifications and constructs, traditional patterns of behaviour that are used in certain typical situations (Natanson 1970: 110). In other words, an individual understands and knows his/her contemporaries not via the direct contact, but via the interpretational scheme of ideal types (Schutz, 1967: 186). Here A Schütz distinguishes two characters of this ideal type, calling them "personal" and "course-of-action" ideal types. In the first case it is the ideal type of another person who expresses himself/herself in a certain way, in the second case – the ideal type of the visible outcome or the expression process itself. Thus, under the interpretational scheme of ideal types, the individual is able to move from the primordial experience of *You* in the direct *We-relationship* to the more anonymous relationship, connecting him/her as a contemporary with other contemporaries as a successor to predecessors, or as a predecessor to the future successors. From the perspective of the subjective interpretations, the social world is constituted precisely via these personal and course of action ideal types both in the relations with more or less familiar people and completely anonymous individuals (Natanson 1970: 111).

The intersubjective lifeworld of daily life is also a place of actions because its living entities act themselves and face the actions of other subjects. It is exactly the analysis of a social action that A. Schütz pays a considerable attention to (2.3.3.). He takes over M. Weber's conception of a social action; however, on the basis on the phenomenological insights, A. Schütz seeks to improve his postulate concerning the interpretation of a subjective meaning. To that end, A. Schütz introduces three dimensions of time (the past, present and future), in respect of which the meaning of an action can be seen. According to A. Schütz, a social action is oriented towards a specific target. The action, which has no projections at all or, more simply, has no objective, is meaningless. This reveals that a social action performed in the present is meaningful because it is projected by the thinking consciousness as the already done (Wing-Chung, 2008: 387). In summary, it is possible to state that the perspective of the future time is absolutely necessary in order to understand the action happening in the present, just as the present is necessary to actualize and reflect upon the actions of the past as meaningful ones. Exactly the same perspective prism of time is adapted by A. Schütz in order to perceive all the subjectively significant human experiences. He explains that the meaning is the result of the interpretation of our past experiences shaped from the

current point of view in a reflective way (Schutz, 1962: 210). Finally, A. Schütz concludes that all of our conscious behaviour in life is the subjectively meaningful experiences (Schutz 1962: 211).

The main insight of the interpretations of the subjective purpose of an action is based on the question how we understand the reasons of an actor (2.3.4). For this purpose, A. Schütz introduces two types of the reasoning concepts: the motives of "in order to" (oriented towards the ultimate goal – the implemented project of an action) and "because of" (the reasons of performed actions) (Schutz 1962: 69). The first group of motives has the entirely subjective meaning, which can only be understood by an actor himself/herself during the performed or projected action. The second group of motives – "because of" – is in principle an objective category that can be characterized by an objective meaning accessible to the outside observer, which can restored by him/her taking the already performed action as a basis (Schutz, 1962: 71). Thus, the mutual understanding among the subjects acting in the lifeworld is motivational, i.e. based on the understanding and, most likely, on the prediction of the possible reasons for an action of each other. A. Schutz calls this phenomenon the "reciprocity of motives", which is also complemented by the other thesis – the reciprocity of prospects on which the intersubjective understanding of another person as alter ego in the lifeworld is based.

The third chapter of the dissertation "THE METHODOLOGY OF THE EMPIRICAL STUDY OF THE LIFEWORLD" is designed to introduce the study methodology and methods.

The choice of the study methodology involved the search for a methodological tool providing the possibility to analyze the daily experiences of social actors living with disability, which in the narrative form is conveyed by them. Consequently, the methodology of the phenomenological sociology has been purposefully chosen for the study in order to phenomenologically analyze the lifeworld of the people with motor disability, and at the same time to stay within the framework of sociological research. In respect to the natural attitude the methodological perspective of the phenomenological sociology by A. Schütz is intended to examine the lifeworld of social actors as the world of things and relationships that are meaningful for them. In other words, A. Schütz chose

to examine social phenomena from the subjective perspective of the lived experience of an individual.

Since A. Schütz refers to the provision that "both physical and social, cultural world is experienced as typified from its beginning" (Schutz, 1971: 233), the lifeworld of people with motor disability can be analyzed as a social world, which is intersubjectively experienced in the typified way and is examined by the investigator from the perspective of these types, based on their systems of significants and relevancies.

Alfred Schütz does not provide any specific methodological steps for the empirical investigation of the lifeworld; consequently, the qualitative research methods recommended by Karin Dahlberg and other scientists in the Scandinavian group are invoked for the study of this thesis (Dahlberg at all, 2008), as they are considered the most suitable for the phenomenological analysis of the lifeworld of people with motor disability. This is a unstructured in-depth interview method (used for the data collection), while the principles of the qualitative content analysis are employed for the obtained data processing, using the *NVivo* computer program for the qualitative data analysis, as well as the principles of the interpretative analysis of text data.

The chapter also presents the site of the study – the Resort of the Lithuanian Association of Paraplegics in Monciškės, the socio-demographic characteristics of the disabled informants of the study, and as well as the steps of the data analysis and the display of subjective position of the researcher.

The fourth part of the thesis "THE LIFEWORLD OF THE PEOPLE WITH MOTOR DISABILITY" consists of eight chapters. It is committed to the analysis and interpretation of the data of the qualitative research.

1. "Disability experienced as a biographical disruption". This chapter of the dissertation, which is divided into four subchapters, reveals a detailed analysis of the disability as a biographical disruption of the people who acquired motor disability at the later stage of their life. Moreover, the chapter also concentrates on the factors determining the acquisition of different meanings of disability, as well as the evaluation of the changed self-assessment and the changed situation of life of the disabled individuals using new interpretative schemes. The first subchapter (4.1.1.) examines an early experience connected with disability and seen by the informants as the collapse of their natural, commonsense reality of the daily lifeworld. The second subchapter (4.1.2.)

analyzes the process of the identity transformation manifesting itself in the loss of the former "abled" self and the integration of the individual identity of a new disabled self revealed in the narrations. The third subchapter (4.1.3.) shows how the disability transforms the subjective reality of people in wheelchairs, which they have to reinterpret with the help of the re-socialization and new systems of meanings and typifications. The final subchapter (4.1.4.) discloses the role of the relationships between a person, who has just become disabled, and other significant ones in the process of re-socialization.

The disability a man is confronted to paralyzes the normal and basic ability to move and rocks the foundations of his/her life, breaks the routine of the established social practices and roles, i.e. as if destroys the entire biography, dividing the biographical time into two periods: before and after the occurrence of disability. As a result, the disability becomes a significant factor determining further biographical situation of a person, who due to the limited mobility, in many cases, changes not only the style of his/her life, as well as the professional or other type of occupation, but in general, the attitudes towards himself/herself and life; here the reappraisal of values can be observed.

The suddenly emerging disability, which takes the ability to walk away, destroys not only the natural attitude of the individual towards the self-evidence of the lifeworld as such, but also ruins the entire structure of the reality of daily life, which also has to be restored during the re-socialization. However, due to irreversible physical changes the former reality of daily life cannot be fully restored – it undergoes a transformation that requires a new valid explanation. Therefore, the individual has to re-interpret the events of his/her biography in the light of the event of disability in order the disability caused disruption between his/her body, self and the world would be fixed, and the value of his/her status as a disabled person would be established, first in his/her own eyes, then in the view of the society. Finally, the re-socialization process of an individual with disability cannot proceed without a positive role of other significant ones, which manifest itself in the form of the physical assistance and care of the fellow-men, especially in the early posttraumatic period, the moral support and efforts of the friends not leaving him/her in the complete social isolation, as well as the inspiring examples of other people with disabilities successfully living their lives.

Not in every case, after such a biographical disruption the re-socialization occurs. Some part of newly disabled people emphasizes the advantage of the former life and the loss of social roles, and perceives the present situation as useless, pointless and providing no possibilities for them to restore the former social activity. Such people transfer the emphasis from the original "here and now" paramount reality that does not satisfy them at all to the sub-world of fantasy or most likely, the sub-world of virtual video games, Internet or cinema, with the help of which they flee from the undesirable and depressing reality of the disability to the other, imagined reality which is not restricted by an immobile body.

2. "The disability experienced as commonsense". In this chapter of the dissertation, consisting of three subchapters, the perception and experience of the people with a congenital disability or having a disability ever since their childhood during the initial (4.2.1.) and secondary periods of socialization (4.2.2.) are presented. The final sub-chapter (4.2.3.) examines the search for the disability legitimation via the reinterpretation of one's own situation of the biography and the accumulated experience of living with disability from the present positions.

The congenital motor disability or the one acquired in childhood is realized not via a direct relationship with one's body, but via social an awareness, which is obtained from a broader social environment during the secondary socialization, and in which the typifications of a disabled, "different", "abnormal" body occur and is associated with a mark of negative connotations – a stigma. To free oneself from the "spoiled" identity (Goffman 1968) it is not enough to invoke the circle of the first socialization involving the significant others; here a new social group or community as a structure ensuring the persuasiveness is necessary, as here the person with disability can develop a positive personal identity opposite to the one that is stigmatized and imposed by the society. The successfully socialized people with disabilities return to the primary experience connected with their disability as the commonsense and natural reality only when it becomes an integral part of their identity, their self, and these people tend not longer to overestimate it in their daily lives and not to isolate it from the rest of the elements of their life reality.

**3.** "The attribute marking a disability: a wheelchair." The separate subchapters of this chapter present the relationship between a wheelchair and the people

having a congenital disability or have acquired it in the childhood and the individuals having it since the later stage of their life, as well as the different meanings attributed to it. Since the person with a motor disability is inseparable from the basic attribute that identifies him/her in the eyes of the society – a wheelchair – it becomes a sign marking the reality of disability. The first sub-chapter (4.3.1.) distinguishes the importance of the re-socialization for the positive change of the relationship between a wheelchair and the individuals who have become disabled after a physical injury or illness; the second sub-chapter (4.3.2.) covers a rather emotional and multi-meaningful relationship between a wheelchair and the people who have congenital disability or have acquired it in the childhood; here this link is clearly different between the representatives of the younger and older generations. The contrast of the relationships between a wheelchair and the members of the society with or without the motor disability, which discloses the paradoxically opposite symbolization of the reality of a disability, is also revealed in the end of the chapter.

4. "The body affected by a disability." In this chapter (consisting of three subchapters), according to the narrations of the informants, the analysis of the experienced disabled body is performed in order to reveal how his/her owner faces the world as a disabled person, and in what senses his/her relationship with the world – as well as with his/her body, which is also a part of the world – is coloured. The chapter also attempts to disclose how the scale of meanings of this relationship is changing, when it is disrupted by the sudden disability and what is special about the existence of the individual having a disability since childhood, what is his/her experience in the relationship with the world without having a healthy body, except for the visible bodies of other non-disabled people.

The disability acquired by the people at a later stage of their life is experienced as a certain disobedience of the body, i.e. the discrepancy between the intentions to move and the movement itself. The loss of tactile sensations in the separate parts of the body complicates the subject's relationship with the world because in the case of the non-sensitive areas of body the contact with the world is indirect, i.e. created via some other part of the body as an intermediary. Moreover, the environment surrounding the person reminds of and shows his/her disability as it leads to the usual intentions, which he/she is no longer able to realize; the surrounding or arising objects and the things he/she cannot

reach or is unable to use, makes him/her turn back to the deficiency hiding in his/her body and confront its limitations.

The individuals having a congenital disability or acquired it in the childhood do not give any prominence to their body disfunctionality or limited capacity to move, and do not focus on the disability as a certain problem or the hindrance to their existence in the world, because ever since an early age they are in constant contact with the world via the body affected by the disability. On the other hand, for them a physical disability is actualized in their interactions with other non-disabled corporeal subjects, as well as in confrontation with the physical objects occurring in their living environment, which due to their disability are unavailable to be disposed.

**5.** "The lived time marked by the disability." This chapter of the dissertation presents the way the subject with a disability perceives the lifeworld via the natural attitude and in respect of time. The two subchapters consider the time experiences reflected by the informants, directed towards the future (4.5.1.), and settled in the personal stock of experiences and knowledge, together with major biographical events (4.5.2.). The last subchapter, in its turn, analyzes the present biographical situation of the disabled people in terms of the subjective time flow and its disposal (4.5.3.).

The strongest reflections on the time experiences are characteristic to the individuals, who acquired a disability at a later stage of their life, because they have undergone the changes not only in their corporeal identity, but also in the experienced time. Moreover, due to the changed body state and the movement in a wheelchair more time is necessary for their daily routine practices. As a result, the people that have experienced a disability suffer from the slowing life rhythm, and thus, are confronted with the contraction of the scope of an activity (especially the spontaneous one), because they are constantly forced to design the horizon of their own future actions and correctly to prepare for their implementation.

Turning to the past time, the people with disabilities reinterpret their past events in the present, according to newly formed interpretational patterns. The obvious difference in the interpretation of the past time of life can be obviously observed between the people with disabilities, depending on the nature of their disability (congenital or acquired later), as well as on the factor of the social isolation/resocialization. The people having disabilities from an early age, perceive the history of

their experiences through the pretty consistent prism of the conventional biographical categories, highlighting the significant experiences associated with the disability that gives meaning and provides the sense of order for their current life situations. Some of them distinguish very significant experiences of the late childhood or early adolescence related to the bullying from their peers and/or social isolation, as the event determining an extremely important change in their life, experienced in the flow of the past experiences. Other people, in their turn, concentrates on the final sit in a wheelchair as a certain critical time, marked by the painful feelings of the lost hope to walk, while the third group of people with disabilities accentuate the realization of their personal dignity and liberation from the imposed stigma of social disability as an significant turning point in their lives.

The individuals, who acquired the disability at a later stage of life, tend to divide the lived time in two biographical periods: before and after the disability has occurred. This indicates that for the person, who has become disabled, an invasion of the disability is almost the most significant event that have determined the further course of his/her life and changed in it. However, here the factor of the re-socialization, according to which the disabled individuals' interpretation and understanding of the biographical situation of their lives can be typified, is an important. Due to the lack of motivation or the physical ability to work the people, who have become disabled but have not experienced the resocialization and turned into socially passive individuals, mark an occurrence of the disability as a decisive moment of their biography, after which the entire flow of all their life experiences is coloured in the negative tone without much expectation of positive change in the future. Meanwhile, those who have re-established their social activity after an occurrence of the disability do not use any diametrically opposed assessment categories of "black-white", "positive-negative" for these biographical periods. They perceive an occurrence of the disability not as a tragic event of their life, but as a new perspective of life and the reality opening up new opportunities for self-realization, or simply understand this as a changed way of life, conditioned by the movement restrictions of a disabled body.

**6.** "The embodied space from the perspective of the person moving in a wheelchair." First of all, this chapter examines the way the people with a motor disability experience the surrounding environment in terms of space; the way they

experience confronting the public (4.6.1.) and their home environments (4.6.1.) moving in a wheelchair; the kind of relationship they create with the surrounding objects – the things in the house, buildings, street infrastructure and so on.

The standard lived experiences of the disabled persons lead them to the common, intersubjective vision and its corporeal sensation of space from the perspective of movement in a wheelchair. First, the surrounding space and its objects are experienced and perceived by these people in the functional sense as closely related to the adaptation to moving in a wheelchair. They do perceive Lithuanian public spaces with buildings in various cities and towns as minimally fitted to their needs and actualizing the inability of their body, because these individuals are often exposed to the buildings or their elements that prevent them from free movement in a wheelchair. The experience of the better adjustment of the physical space in cities and towns to the movement of the people with disabilities is quite a significant factor affecting their quality of life, as well as the positive relationships with the environment and themselves.

At home that is adequately adapted to their needs the disabled individuals experience the unity of their body and the surrounding area, which mitigates the sense of a impairment in the body, prevents the actualization of a disability and gives an opportunity to become more or completely independent, as well as to organize the social activity according to their interests. However, the people with disabilities representing the younger generation and seeking the employment, avoid to close themselves in the home environment, as a result of which in order to expand their social network and to maintain an active and direct communication with other people they want to have an opportunity to work outside its boundaries, this way not restricting themselves to work and communications at home via the virtual web space or other higher technologies.

7. "The peculiarities of the social interaction between the members of a society with or without a motor disability." This chapter discusses the relationships between the members of a society with and without disabilities constructed in various interactions, characterized by the division of the in-group and out-group (4.7.1.), as well as the stigmatized and lower social status imposed on the disabled person (4.7.2.), and the lack of the intersubjective understanding in the interactions between "healthy" and disabled individuals (4.3.3). The study results reveal the lack of knowledge concerning the people with a motor disability presented by a large part of the non-disabled members

of the society. This lack of knowledge supports the predominance of stereotypical attitudes towards the people with disabilities, as well as the building of the unequal, stigmatized relationships with them.

**8. "Visualization of the empirical data analysis".** This final chapter visually (by charts) discloses the most important results of the interpretative text analysis, illustrated by the extracts from the narrations of the subjects.

### CONCLUSIONS

- 1. Phenomenological concept of disability, integrated into the social model of disability, gives the possibility to analyze the phenomenon of disability from the positions of embodies disabled subject, overcoming Cartesian dualism of mind and body, i.e., including the problems of both subjectively lived body impairment and the origin of social disability. On the one hand, this subject is affected by the system of social relationships, on the other hand, it also creates, maintains and interprets the social reality through every day practices.
- 2. According to A. Schütz's concept of lifeworld, the world of persons with motor disability reveals as a social reality, which is important to them. These persons experience and perceive it intersubjectively, following a natural attitude. Their relationship with the world is distinctive and unique because of disabled body and experience of movement with a wheelchair, as well as knowledge, which is not had by non-disabled members of society. Therefore, in many cases the content of meanings, which are attributed to various situations of life with disability by disabled ones, appears to be more positive and does not meet the stereotypical attitudes about persons with disabilities, prevailing in society.
- The narrations of disabled persons, collected and analyzed during research, allows distinguishing two significant types of persons with motor disability due to their differently lived and interpreted experience of disability.
  - a. A person, who has been disabled since childhood, experiences the change of self-consciousness and the natural world view, related with the realization of his/her physical disability. During secondary socialization the aforementioned person faces a broader social environment that impress on him the typifications of "different", "abnormal", i.e., disabled body, causing the stigmatizing effects on his/her identity formation.
  - b. The successful socialization of person with disability from an early age requires an alternative, new social group or community, i.e., the social structure, which helps to overcome the internalized negative social typifications and to create new senses, establishing his/her positive identity.
  - c. The disability, occurring at a later stage of life, causes a turning point in

biography. Experienced disability substantially disrupts the established social practice, changes social roles. Biography is divided into two periods: before and after disability. The changes of body destroy individual and social identity. Reconstruction of identities requires a new sense structure of subjective reality, legitimating a disability in person's life. The positive relationship with social environment, which is important for that person and which enables his/her resocialization, is also required.

- 4. Persons, who have become disabled suddenly, experience the disabled body as a rigid, resisting to internal intention to manage it, the limbs, which lost tactile sensations of the body as silent body areas, which are no longer in active relationship with the world. Since childhood the disabled body is experienced as a matter of course, a part of the natural world view. Physical disability rarely becomes the subject of mind, i.e., observed and reflected, in everyday routine. However, in both cases the motor disability manifests and actualizes as an internal mismatch between active self and own body, which is a passive plane of identity. Surrounding world and its physically unavailable, inaccessible, not suitable for use things or other objects constantly remind the defect of their body. This also demonstrates the social side of nature of phenomenon of disability.
- 5. A wheelchair, an integral part of everyday life of people with motor disability, is not only simple compensatory technique, but also the sign, symbolizing the differently lived reality of disability. Various meanings, which are attributed to it, depend on both different experience of each individual and knowledge, the nature of disability (since childhood or after traumatic event, result of illness), and on the perspectives of individual's time, lived with disability, as well as characteristics of resocialization process.
  - a. For people, who have been disabled since childhood, a wheelchair is an integral part of their lifeworld. Young people consider a wheelchair as a measure of self-representation, while for older ones it acquires the meanings of sociality, mobility and even embodies the desire for freedom and independence from the help of others (electric wheelchair).
  - b. Persons, who have experienced a disability at a later stage of life, usually go through adaptation period during resocialization. Then their relationship with

- a wheelchair changes: from the association with irreversibly ruined previous life and very negative meanings of stigmatized identity to neutral ones, when a wheelchair is seen as a basic tool for movement.
- 6. The emergence of disability at a later stage of life (as well as its strong worsening in case of living with it since childhood) slows down a time flow, which is experienced subjectively by disabled person. This slowdown of time flow is determined by slower actions due to limited movement of body. Thus, the elementary body selfservice and routine social practices require more time at the expense of other activities. The meanings, attributed to the time, lived with disability, vary from completely negative to quite positive ones, depending on the characteristics of resocialization. Disabled persons, who have not experienced successful resocialization, attribute a negative meaning of desperately "ruined life" to a new period of their biography. This meaning is associated with a pointless, inane, "empty" spending of time. Successfully resocialized people with disabilities attribute a positive meaning to the time, lived with disability, by experiencing it as a period of new life perspectives and self-realization possibilities. They also use the time for fulfillment of dreams, which have not been realized during previous life (without disability).
- 7. The main feature of intersubjective lifeworld, uniting people with motor disability, is a perspective experience of surrounding space, arising from the position of body in a wheelchair. It determines the formation of typified conceptual system, which is different from people, able to walk, and which is applied for interpretation of lived space (e.g., distances in public spaces, when moving with a wheelchair, are assessed, according to positioning of streets and sidewalk ramps and physical capability to overcome them, and public buildings according to the ability to access them by properly fitted entry). Insufficient or poorly adapted physical environment of public spaces of country towns or villages causes the feeling of unsafe, inhospitable environment, preventing movement and establishing the relationship of dependence on the help of others, which actualizes their disability and determines lower social activity as well as lower motivation of employment outside home boundaries. The environment of residential accommodation, which is usually well adapted to their needs, minimizes the daily experience of physical disability.

- 8. A significant factor is the age of people with disability in assessing their lived space. The youth has no motivation for remote work in its home area and considers it as the factor, increasing social isolation. The older generation of disabled people is more positive in assessing the possibilities of remote work at home. What is more, currently they notice a considerably stronger experience of consistency of their position of body in a wheelchair and a physical environment of surrounding public spaces. The different interpretation of living space of disabled is determined by their as disabled persons' experience, gained during difficult social situation of Soviet period, which the youth does not have.
- 9. It might be stated that a lack of intersubjective (mutual motivational) understanding exists in social interactions of people with motor disability and other members of society. It arises from differently formed typifications and interpretational schemes, which are followed by members of these groups. The mentioned lack of understanding evidences by unrequested charity of passersby for people sitting in a wheelchair, open display of compassion or its expression, bored staring at them and similar actions, which are undesirable by disabled. This shows that society is still not familiar with the social reality, lived by disabled persons. Due to this unfamiliarity during social interactions the disabled members of society are imposed with unequal relationships: they are stigmatized and classified as having a lower social status.
- 10. Social and health care professionals also show their social power in relationship with disabled ones. In the primary health care institutions they are generally classified as "second-class" patients, who lack proper attention from professionals. These experiences, reflected by disabled people, show the existing trend of medical professionals to follow the biomedical and functionalist view towards a disabled person as towards an incurable patient and useless member of society. Although employees, providing social services for people with disability, or supervising professionals should be well aware of living specificity of people with motor disability, should be able to provide a competent support, however, in many cases the disabled ones argue that these professionals do not have the aforementioned characteristics, and the nature of social interaction with them is unacceptable.

## **IVADAS**

Tyrimo aktualumas ir problema. Nuo seno žmonės neįgaliaisiais buvo laikomi ne dėl savo poreikių išskirtinumo ar negalios dydžio, bet pirmiausia dėl to, kad didžiausias dėmesys buvo kreipiamas būtent į jų silpnąsias, išskirtines savybes. Taigi pirmiausia buvo akcentuojama, kuo jie skiriasi nuo kitų, ir visai nekreipiamas dėmesys, ką jie turi bendra (Gudonis, Novogrodskienė 2000). Toks požiūris į neįgaliuosius yra išlikęs ir mūsų dienomis. Judėjimo negalią turintys asmenys išsiskiria savo išorinėmis savybėmis, neatitinkančiomis "normalaus", arba "standartinio", žmogaus įvaizdžio, todėl jie tampa ypač savita visuomenės socialine grupe, kurią likusieji visuomenės nariai dažniausiai suvokia ir vertina kaip priklausančius "jie" grupei, t. y. kitokių, svetimų, nepažįstamų ir vengtinų žmonių grupei. Tai atsitinka būtent dėl kitokios, "nenormalios" kūno išvaizdos ir sėdėjimo neįgaliojo vežimėlyje. Tarp šių žmonių ir kitų visuomenės narių egzistuojantis socialinis nuotolis trukdo neįgaliųjų integracijos procesui. Dėl neigiamų nuostatų neįgaliųjų atžvilgiu susidaro kliūtys jiems įsilieti į socialinį, kultūrinį, politinį bei ekonominį visuomenės gyvenimą bei tapti visaverte jos dalimi.

Socialinės apsaugos ir darbo ministerijos socialinio pranešimo (2010: 149) duomenimis 2009 m. šalyje gyveno 269 033 neįgalūs asmenys, sudarantys apie 7,5 proc. Lietuvos gyventojų. Maždaug ketvirtadalis iš jų turi sutrikusią judėjimo funkciją (Tretjakova 2006: 138). Neįgalių žmonių skaičiaus augimo tendencijos nors ir nežymios, bet kasmet išlieka. Didėja ir judėjimo negalią turinčių, ypač patyrusių stuburo traumas žmonių skaičius. Be to, labai daug žmonių neįgaliais tampa būdami darbingo amžiaus ir palyginti mažai jų sugrįžta į darbo rinką, likdami ekonomiškai neaktyvūs visuomenės nariai. O šalyje vykdomų neįgaliesiems skirtų profesinių reabilitacijos programų efektyvumą mažina nepakankamas darbo vietų ir viešosios aplinkos pritaikymas vežimėliu judantiems asmenims (Gruževskis 2008: 90; 130).

Todėl kyla vis didesnis poreikis tyrinėti ir analizuoti šį socialinį reiškinį, kuris yra toks nevienalytis ir daugiamatis, kad negalios sampratų apibrėžties klausimas ligi šiol yra pamatinė negalios sociologijos problema (Abberley 2002: 79). Joje vis dar vyksta priešingų teorinių perspektyvų ginčas, aiškinantis, kuri negalios samprata yra teoriškai tikslesnė, artimesnė šio reiškinio tikrovei. Taip pat stebima tendencija išsiveržti iš tradicinių – biomedicininio ir socialinio – negalios modelių ir ieškoti naujų teorinių

prieigų, kurių ašimi būtų pagrindinis šio reiškinio subjektas – negalią turintis asmuo. Dar mažai žinoma, į kokią socialinę tikrovę jis patenka, atsisėdęs į neįgaliojo vežimėlį po nelaimingo įvykio? Kas yra negalia, kokią reikšmę ir vaidmenį gyvenime ji užima nuo mažens su vežimėliu judančiam? Kaip šie žmonės išgyvena jiems primetamą neįgaliojo socialinį statusą ir apskritai visą socialinę tikrovę? Tuo labiau, kad dauguma visuomenės žinių apie neįgaliuosius gauta ne iš jų pačių, o tėra visuomenės nuomonė apie juos (Šeporaitytė, Tereškinas 2007: 20). Todėl labai svarbu išgirsti, kaip patys neįgalieji suvokia ir išgyvena negalią bei savo socialinę tikrovę.

Tyrimai, kurie yra pagristi pozityvistine paradigma, nėra pajėgūs atskleisti subjektyvios negalios tikrovės, kuri išreiškiama per vidines toje tikrovėje veikiančių subjektų patirtis. Būtent Alfredas Schützas, fenomenologinės sociologijos krypties pradininkas, tvirtina, jog tam, kad būtų galima suprasti ir moksliškai analizuoti socialinį pasaulį, reikia atsigręžti į pačius socialinius veikėjus, kuriems šis pasaulis egzistuoja ir kuriame jie yra veikiantys bei patiriantys subjektai, susisaistę vieni su kitais įvairiausiais socialiniais ryšiais ir tiems ryšiams bei visai patiriamai tikrovei priskiriantys savitas, subjektyvias prasmes (Schutz 1967: 10). Socialinį pasaulį Alfredas Schützas nagrinėja pasitelkdamas fenomenologine gyvenamojo pasaulio samprata, kuria iis, pakoregaves socialine ir pragmatine kryptimi, pritaiko interpretatyvinei sociologijai. Tad remiantis A. Schützo fenomenologine perspektyva, sociologija turi sutelkti dėmesį ne ties socialinėmis struktūromis (socialiniais institutais, klasėmis ar kt.), bet ties kasdienybėje patiriančių subjektų gyvenamuoju pasauliu (Overgaard & Zahavi 2009: 15). Tai paprastų socialinių veikėjų intersubjektyviai, t.y. panašiai ar bendrai patiriamas kasdienio gyvenimo pasaulis, kuriame subjektai vadovaujasi natūralia nuostata, jog tiesiogiai patiriama socialinė tikrovė yra faktiškai objektyvi ir visi dalykai joje priimami kaip savaime suprantami ir nekvestionuojami.

Taigi A. Schützo sociologinės fenomenologija, kuri laiko socialinius veikėjus aktyviais prasmės kūrėjais, o ne išoriškai ir objektyviai apibrėžtų reikšmių gavėjais, padeda atskleisti, kaip neigalūs žmonės supranta ir interpretuoja negalią ir su ja susijusius savo gyvenimo faktus bei reiškinius, išgyventus socialinių situacijų bei sąveikų metu.

Judėjimo negalią turinčių žmonių *gyvenamasis pasaulis* yra savitas ir išsiskiriantis iš kitų socialiai reikšmingų grupių tuo, kad yra persmelktas bendros, arba, kitaip tariant,

intersubjektyvios, kūno negalios patirties, kuri yra centrinė visos šių žmonių gyvenamojo pasaulio analizės ašis. Judėjimo negalios atveju kūnas arba nuo mažumės pasižymi kitokiomis, nei vaikštančio žmogaus, savybėmis, arba vėlesniame gyvenimo tarpsnyje dėl ligos ar traumos patiria tam tikras modifikacijas, dėl kurių pasikeičia jutimai, keičiasi judėjimo erdvėje galimybės ir aplinkybės, tad ir šio kūniškojo subjekto santykis su pasauliu.

Pagal fenomenologinę tradiciją kūno santykis su pasauliu nuo pat pradžios yra prisodrintas prasmės, nes pasaulis kūniškajam subjektui yra išgyvenamas pasaulis, jam reikšmingas pasaulis (Sadala, Adorno 2002: 286). Todėl šiuo tyrimu siekiama atskleisti, kaip tiriamieji, pasitelkdami naracijas (giluminio interviu metu), subjektyviomis prasmėmis kuria ir konstruoja jiems reikšmingą socialinę tikrovę, kaip jie įprasmina savo santykį su pasauliu, kokias reikšmes jam suteikia, išgyvendami ir suvokdami jį per neįgalų kūną.

Taigi disertacijos **mokslinę tyrimo problemą** sudaro esminis klausimas: kokia yra judėjimo negalią turinčių asmenų subjektyvi socialinė tikrovė, atskleidžiama pasitelkiant Alfredo Schützo fenomenologinę *gyvenamojo pasaulio* sampratą?

Tyrimo objektas – judėjimo negalią turinčių asmenų gyvenamasis pasaulis.

Tyrimo tikslas – remiantis fenomenologinės sociologijos teorine perspektyva ir judėjimo negalią turinčių žmonių naracijomis ištirti neįgaliojo vežimėliu judančių asmenų intersubjektyviai patiriamą ir suvokiamą socialinę tikrovę, gilinantis į pagrindines fenomenologines gyvenamojo pasaulio temas: santykį su savo neįgaliu kūnu, išgyvenama erdve ir laiku bei reikšminga artimiausia ir anonimiška įgaliųjų/institucionalizuota socialine aplinka.

## Tyrimo uždaviniai:

- Apibrėžti teorinius negalios sampratos modelius, jų prieštaros problematiką bei kaitos tendencijas sociologiniame diskurse.
- 2. Išnagrinėti Alfredo Schützo gyvenamojo pasaulio sampratą, kuria remiantis fenomenologinėje sociologijoje analizuojama socialinė tikrovė.

- Empirinio fenomenologinio tyrimo pagrindu rekonstruoti judėjimo negalią turinčių asmenų gyvenamąjį pasaulį kaip intersubjektyviai patiriamą ir vadovaujantis natūralia nuostata suvokiamą šių žmonių socialinę tikrovę.
- 4. Išryškinti specifinius gyvenimo su judėjimo negalia (įgimta/nuo vaikystės ir vėliau įgyta) bruožus, įtraukiant neįgalių asmenų subjektyvias santykio su savo kūnu, jo neįgalumu ir nuolatine judėjimo priemone vežimėliu patirtis, išgyvenamos erdvės bei laiko, o taip pat ir socialinių sąveikų su negalios neturinčiais visuomenės nariais ypatumus.

# Ginami teiginiai

Atlikto tyrimo pagrindu disertacijoje ginami šie teiginiai:

- Judėjimo negalią turinčius asmenis galima tipizuoti pagal skirtingai išgyvenamą ir interpretuojamą negalios patirtį į du atskirus tipus: nuo vaikystės neįgalūs ir vėlesniame gyvenimo tarpsnyje neįgaliaisiais tapę:
  - Nuo vaikystės neįgalūs asmenys susiduria su negalia tik antrinės socializacijos metu, internalizavę socialines negatyvios reikšmės neįgalaus kūno tipizacijas, kurioms įveikti ir sėkmingai socializuotis būtina įsitraukti į naują jiems socialinę grupę ar bendruomenę, t.y. pozityvią, jų identitetą patvirtinančią socialinę struktūra.
  - Vėlesniame gyvenimo tarpsnyje asmenį ištikusi negalia įgyja biografinio lūžio reikšmę, nes palieka pėdsakus ne tik jo kūne, bet taip pat keičia ir tapatybę bei visą subjektyvią socialinę tikrovę, kuriai reikalinga nauja prasmės struktūra, leidžianti įvykti individo resocializacijai.
- 2. Judėjimo negalia kaip intersubjektyviai išgyvenamas kūno fenomenas pasireiškia vidiniu neatitikimu tarp aktyvaus Aš ir pasyvia tapusios fizinio kūno dalies. Negalia aktualizuojasi neįgalaus asmens sąmonėje per jo kūnišką santykį su aplinkiniu pasauliu ir jame esančiais fiziškai neprieinamais, nepasiekiamais objektais.
- Igyta judėjimo negalia sukelia neįgaliu tapusio asmens išgyvenamo laiko pokyčius, kurie pasireiškia subjektyvios laiko tėkmės sulėtėjimu, naujomis (negatyviomis ar pozityviomis) prasmėmis, priskiriamomis gyvenamam su negalia laikui ir jo panaudojimui.

- 4. Vežimėliu judantys neįgalieji gyvenamojo pasaulio erdviškumą patiria ir suvokia pirmiausia per savojo kūno padėties ir fizinės aplinkos (ne)dermės išgyvenimą. Tad jų požiūriu viešosios mūsų šalies erdvės vis dar išlieka menkai pritaikytos riedėti neįgaliojo vežimėliu.
- 5. Fiziškai neigalūs asmenys susiduria su vyraujančiu socialiniu žinojimu apie juos, paremtu tipizacijomis, neatitinkančiomis jų išgyvenamos tikrovės vaizdo. Šis žinojimas sudaro palankias sąlygas pasireikšti įgalių visuomenės narių socialinei galiai, sukuriant ir palaikant socialinių sąveikų metu nelygiaverčius santykius su judėjimo negalią turinčiais asmenimis.

# Tyrimo metodai

Tyrimo metodologija remiasi A. Schützo fenomenologine sociologija. Tačiau jis negali būti priskiriamas fenomenologinės sociologijos studijai griežtąja prasme, nes jis nukreiptas ne tiek į būdus, kuriais socialiniai veikėjai – judėjimo negalią turintys asmenys – vadovaudamiesi natūralia nuostata konstituoja išgyvenamą socialinę tikrovę subjektyvioje sąmonėje, kiek į į šių asmenų išgyventos patirties, susijusios su neįgaliu kūnu ir funkcionavimu šiuo kūnu socialiniame pasaulyje, prasmes ir turinį. Be to, gyvenamojo pasaulio analizė praplečiama Alfredo Schützo pasekėjų Thomo Luckmanno ir Peterio Bergerio įžvalgomis, jungiančiomis A. Schützo fenomenologinę ir George'o Herberto Meado simbolinės sąveikos perspektyvas, pritaikant jas neįgalių asmenų (re)socializacijos, socialinių vaidmenų įgijimo/praradimo, identiteto nagrinėjimui, taip pat kitų fenomenologų Maurice'o Merleau-Ponty, Edmundo Husserlio, Daliaus Jonkaus bei Donato Večerskio mintimis apie įkūnyto subjekto santykį su pasauliu ir savo kūnu, kitų sociologų įžvalgomis. Tačiau visas jas vienija bendra nuostata, jog socialinių veikėjų subjektyvi patirtis, o ne "objektyvus" faktinis turinys yra lemiamas veiksnys, pagal kurį jie apibrėžia savo situaciją pasaulyje.

**Disertacijos tyrimui atlikti naudojami šie metodai**: mokslinės literatūros analizė ir sintezė, nestruktūruotas giluminis interviu, kokybinė turinio analizė bei tekstinių duomenų interpretacinė analizė.

## Mokslinis tyrimo naujumas

Judėjimo negalia nėra Lietuvos sociologų plačiai analizuojamas reiškinys. Sociologiškai ją yra nagrinėję atskirais aspektais Jolanta Pivorienė (1998, 2001, 2003), Jonas Ruškus (1997, 2002) Rūta Adomaitienė (1999, 2007) kartu su Jūrate Mikelkevičiūte (2001), Deimantė Šeporaitytė (2006) kartu su Artūru Tereškinu (2006a, 2008), Anelė Vosyliūtė (2009) bei kiti. Dažniausiai judėjimo negalią turinčių žmonių kaip atskiros socialinės grupės tyrimai atliekami socialinės gerovės (Ruškus, Mažeikis 2007, Ruškus, Blinsturbas, Žukauskas, Daugėla 2006; Ruškus, Daugėla, Žukauskas, Blinstrubas, Šaparnis 2007; Ruškus, Daugėla, Žukauskas, Blinstrubas, Šaparnis 2007a), socialinės edukologijos ir reabilitacijos srityse (Skučas 2003, 2003a, 2006, Ostasevičienė 2002, Stomienė 2000) bei analizuojant įtraukties į darbo rinką klausimus (Daugėla 2004, Miliauskaitė 2004, Gailienė 2006, Vinikaitytė 2007).

Neigaliųjų socialinio gyvenimo tikrovė fenomenologinėje perspektyvoje Lietuvoje dar nebuvo tyrinėta. Šis tyrimas yra moksliškai reikšmingas tuo, kad atkreipiamas dėmesys į kasdienes gyvenimo su judėjimo negalia patirtis, kurios tyrinėjamos remiantis A. Schützo fenomenologinės sociologijos metodologinėmis gairėmis. Tokiu būdu yra atskleidžiama fiziškai neįgalių asmenų socialinė situacija ir požiūris į patį negalios reiškinį iš subjektyvios jį patiriančiųjų perspektyvos. Tad šiuo tyrimu, atskleidžiančiu subjektyvų, o tiksliau intersubjektyvų neįgaliųjų požiūrį į jų pačių gyvenimo su judėjimo negalia tikrovę, yra pagilinamas sociologinis žinojimas apie šiuos visuomenės narius.

Be to, fenomenologinė gyvenamojo pasaulio analizė atveria įvairiapusį fiziškai neįgalių asmenų suvokiamą pasaulio vaizdą, kuris yra konstruojamas iš jų reflektuotų patirčių, perteiktų naracijos būdu. Tyrimo metu buvo atskleistas neįgalaus asmens santykis su savo kūnu, o taip pat ir su išoriniu pasauliu per neįgalų kūną; jo tapatybės transformacijos problematika įgytos arba socializacijos metu įsisąmonintos negalios akivaizdoje, kuri susijusi su neįgaliajam reikšmingos socialinės aplinkos įtaka. Galiausiai atveriamas savitas neįgalių žmonių erdvėlaikinis gyvenamojo pasaulio suvokimas iš judėjimo neįgaliojo vežimėliu perspektyvos bei pačių neįgaliųjų reflektuota socialinė sąveika su įgaliais visuomenės nariais.

Vėžimėliu judančių neigaliųjų gyvenimo situacija tiek socialiniu, tiek kultūriniu požiūriu yra savita ir skiriasi nuo Vakarų šalių patirties, nes jos esmę nusako specifinis

tautinis mentalitetas bei savita istorinė raida (Ruškus 2002: 15), todėl šis tyrimas yra tikslingas ir vertingas įnašas į mokslinio žinojimo plėtrą apie judėjimo negalią turinčių asmenu socialine tikrove Lietuvos visuomenės kontekste.

# Disertacijos struktūra

Disertaciją sudaro įvadas, keturios pagrindinės dalys, atskleidžiančios teorinius, metodologinius ir empirinius analizės aspektus, darbo pabaigoje pateikiamos išvados, taip pat nuorodos į literatūros šaltinius, priedai.

Pirmosios dvi disertacijos dalys yra teorinės. Pirma dalis "Negalios samprata sociologiniame diskurse" apima keturis skyrius, kuriuose analizuojamas negalios sampratos formavimasis ir požiūrio į šį reiškinį kaitos tendencijos medicinos sociologijoje, taip pat priešingų negalios sampratos modelių atsiradimas, kritinis diskursas jų atžvilgiu bei teorinės prieigos, mėginančios įveikti tradiciniais tapusių negalios sampratos modelių prieštarą.

Antroje teorinėje dalyje "Gyvenamasis pasaulis A. Schützo fenomenologinės sociologijos požiūriu", susidedančioje iš trijų skyrių, pristatomos gyvenamojo pasaulio analizavimo sociologijoje ištakos bei nagrinėjama A. Schützo gyvenamojo pasaulio samprata, atskleidžianti, kaip jame gyvenantys socialiniai veikėjai vadovaudamiesi natūralia nuostata suvokia ir intersubjektyviai patiria juos supančią socialinę tikrovę.

Trečia disertacijos dalis "Gyvenamojo pasaulio empirinio tyrimo metodologija", susidedanti iš trijų skyrių, skirta aptarti empirinio tyrimo metodologines gaires, pristatyti jame naudotus kokybinius metodus bei tyrimo duomenų apdorojimo bei analizės metodiką, pasitelkiant *NVivo* kokybinių duomenų analizės kompiuterinę programą.

Paskutinėje, ketvirtoje disertacijos dalyje "Judėjimo negalią turinčių asmenų gyvenamasis pasaulis", susidedančioje iš aštuonių skyrių, pristatoma kokybinio tyrimo duomenų analizė bei interpretacija. Joje atskirai nagrinėjama nuo mažens turimos ir vėlesniame gyvenimo tarpsnyje įgytos judėjimo negalios patirtis, neįgalių asmenų santykis su vežimėliu bei įvairios jam suteikiamos prasmės. Taip pat fenomenologiškai analizuojama neįgalaus kūno patirtis, išgyvenamas su negalia laikas bei erdvė iš judėjimo neįgaliojo vežimėliu perspektyvos; atskleidžiami socialinės sąveikos tarp įgalių ir neįgalių visuomenės narių ypatumai. Empirinių duomenų analizę užbaigia paskutiniame

skyriuje vaizdiškai (schemomis) pateikiami svarbiausi teksto interpretacinės analizės rezultatai, iliustruoti tiriamųjų naracijų ištraukomis.

### IŠVADOS

- 1. Fenomenologinė negalios samprata, integruota į socialinį negalios modelį, suteikia galimybę analizuoti negalios reiškinį iš įkūnyto negalios subjekto pozicijų, įveikiant karteziškąjį minties ir kūno dualizmą, t. y. apimant tiek subjektyviai išgyvenamo kūno sutrikimo, tiek socialinės negalios kilmės problematiką. Šis subjektas, viena vertus, yra veikiamas socialinių santykių sistemos, kita vertus, per kasdienes praktikas taip pat kuria, palaiko bei interpretuoja socialinę tikrovę.
- 2. Pagal A. Schützo gyvenamojo pasaulio sampratą judėjimo negalią turinčių asmenų pasaulis atsiskleidžia kaip jiems reikšminga socialinė tikrovė. Šie asmenys ją intersubjektyviai patiria ir suvokia vadovaudamiesi natūralia nuostata. Jų santykis su pasauliu yra savitas ir išskirtinis dėl neįgalaus kūno ir judėjimo neįgaliojo vežimėliu patirties bei žinojimo, kurių neturi įgalūs visuomenės nariai. Todėl neretai ir prasmių, kurias neįgalieji priskiria įvairioms savo gyvenimo su negalia situacijoms, turinys pasirodo esąs daug pozityvesnis ir neatitinkantis visuomenėje vyraujančių stereotipinių nuostatų apie neįgaliuosius.
- Tyrimo metu surinktos ir išanalizuotos neįgalių žmonių naracijos leidžia išskirti du ryškius judėjimo negalią turinčių asmenų tipus dėl jų skirtingai išgyvenamos ir interpretuojamos negalios patirties.
  - a. Nuo vaikystės neįgalus asmuo išgyvena savivokos ir natūralaus pasaulio vaizdo kaitą, susijusią su savo kūno negalios įsisąmoninimu. Antrinės socializacijos metu šis asmuo susiduria su platesne socialine aplinka, kuri įteigia jam "kitokio", "nenormalaus", t.y. neįgalaus kūno tipizacijas, sukeliančias stigmatizuojantį poveikį jo tapatybės formavimuisi.
  - b. Sėkmingai nuo mažens neįgalaus asmens socializacijai reikalinga alternatyvi, jam nauja socialinė grupė ar bendruomenė, t.y. tokia socialinė struktūra, kuri padeda įveikti internalizuotas negatyvias socialines tipizacijas ir kurti naujas, itvirtinančias jo pozityvų identiteta, prasmes.
  - c. Vėlesniame gyvenimo tarpsnyje asmenį ištikusi negalia sukelia biografinį lūžį. Patirta negalia iš esmės sugriauna nusistovėjusią socialinę praktiką, keičia turėtus socialinius vaidmenis. Biografija padalinama į du periodus: iki negalios ir po jos. Dėl kūno pokyčių suardomas turėtas individualus ir

socialinis identitetas. Identitetų rekonstrukcijai reikalinga nauja subjektyvios tikrovės prasmės struktūra, legitimuojanti negalią asmens gyvenime. Taip pat būtini pozityvūs santykiai su šiam asmeniui reikšminga socialine aplinka, įgalinančia vykti jo resocializacijai.

- 4. Netikėtai neįgaliais tapę asmenys išgyvena negalios apimtą kūną kaip nepaslankų, nepasiduodantį vidinei intencijai jį valdyti, taktilinius kūno pojūčius praradusias galūnes kaip tylinčias kūno zonas, kurios nebepalaiko aktyvaus santykio su pasauliu. Nuo vaikystės neįgalus kūnas išgyvenamas kaip savaime suprantamas dalykas, natūralaus pasaulio vaizdo dalis. Kasdienybėje kūno neįgalumas retai tampa sąmonės objektu, t.y. pastebimas ir reflektuojamas. Tačiau abiem atvejais judėjimo negalia pasireiškia ir aktualizuojasi kaip vidinis neatitikimas tarp aktyvaus Aš ir savo kūno, kuris yra pasyvioji tapatybės plotmė. Aplinkinis pasaulis per neįgaliesiems fiziškai nepasiekiamus, neprieinamus, netinkančius pasinaudoti daiktus ar kitus objektus nuolat primena jų kūne esantį trūkumą. Tai parodo ir socialinę negalios fenomeno prigimties pusę.
- 5. Neįgaliojo vežimėlis, neatsiejama judėjimo negalią turinčių žmonių kasdienybės dalis, yra ne tik paprasta techninės pagalbos priemonė, bet ir ženklas, simbolizuojantis skirtingai išgyvenamą negalios tikrovę. Jam suteikiamos įvairios prasmės priklauso tiek nuo atskirų individų skirtingai susiformavusios patirties ir žinojimo atsargos, negalios pobūdžio (nuo vaikystės ar po trauminio įvykio, ligos), tiek nuo to paties individo išgyvento su negalia laiko perspektyvų ir resocializacijos proceso ypatumų.
  - a. Nuo mažens neįgaliems asmenims vežimėlis yra neatsiejama, savaime suprantama jų gyvenamojo pasaulio dalis. Jauni asmenys vertina vežimėlį kaip savęs reprezentavimo priemonę, tuo metu kai vyresniesiems jis įgyja socialumo, mobilumo reikšmes ir net įkūnija laisvės bei nepriklausomybės siekį nuo kitų pagalbos (elektrinis vežimėlis).
  - b. Vėlesniame gyvenimo tarpsnyje negalią patyrusieji asmenys resocializacijos metu dažniausiai pergyvena adaptacinį laikotarpį. Tuomet keičiasi jų santykis su vežimėliu: nuo itin negatyvių asociacijų su negrįžtamai sugriuvusiu ankstesniu gyvenimu bei stigmatizuotos tapatybės reikšmių iki neutralių, kai vežimėlis vertinamas kaip elementari judėjimo priemonė.

- 6. Negalios atsiradimas vėlesniame gyvenimo tarpsnyje (taip pat ir ryškus jos sunkėjimas gyvenant su ja nuo vaikystės) sulėtina neįgalaus asmens subjektyviai išgyvenamą laiko tėkmę. Šį laiko tėkmės sulėtėjimą sąlygoja dėl riboto kūno judėjimo lėčiau atliekami veiksmai. Tad elementarios kūno apsitarnavimo ir rutininės socialinės praktikos reikalauja daugiau laiko sąnaudų kitos veiklos sąskaita. Priklausomai nuo resocializacijos ypatumų gyvenamam su negalia laikui suteikiamos prasmės varijuoja nuo visiškai negatyvių iki ganėtinai pozityvių reikšmių. Neįgaliais tapę asmenys, nepatyrę sėkmingos resocializacijos, naujam savo biografijos periodui priskiria negatyvią beviltiškai "sugriauto gyvenimo" reikšmę. Ši reikšmė susijusi su netikslingu, neturiningu, "tuščiu" laiko leidimu. Sėkmingai resocializavusieji asmenys savo naująją nuo negalios atsiradimo prasidėjusią biografinio laiko atkarpą vertina pozityviai, kaip naujų gyvenimo perspektyvų ir savirealizacijos galimybių atsivėrimo metą. Jie taip pat laiką išnaudoja ir ankstesniame (iki negalios) gyvenimo tarpsnyje nerealizuotoms svajonėms įgyvendinti.
- 7. Pagrindinis judėjimo negalią turinčius asmenis vienijantis intersubjektyvaus gyvenamojo pasaulio požymis yra *perspektyvinis supamos erdvės patyrimas, kylantis iš kūno, esančio vėžimėlyje, pozicijos*. Jis sąlygoja tipizuotos, skirtingos nuo vaikštančių žmonių, prasminės sistemos susiformavimą, taikomą išgyvenamai erdvei interpretuoti (pvz., atstumai viešosiose erdvėse judant vežimėliu vertinami pagal gatvių ir šaligatvių nuovažų išsidėstymą ir fizinį pajėgumą juos įveikti, o visuomeninės paskirties pastatai pagal galimybę į juos patekti tinkamai įrengta įvaža). Nepakankamai arba prastai pritaikyta šalies miestų ar gyvenviečių viešųjų erdvių fizinė aplinka sukelia neįgaliesiems nesaugios, nesvetingos, trukdančios judėti bei sukuriančios priklausomybės santykį nuo kitų pagalbos aplinkos pojūtį, kuris aktualizuoja jų negalią ir sąlygoja mažesnį socialinį aktyvumą, o kartu ir mažesnę darbinio užimtumo motyvaciją už namų erdvės ribų. Gyvenamojo būsto aplinka, kuri dažniausiai yra gerai pritaikyta jų poreikiams, iki minimumo sumažina kasdienį kūno neįgalumo išgyvenimą.
- 8. Vertinant išgyvenamą erdvę, ženklus yra neįgaliųjų amžiaus veiksnys. Jaunimas visiškai neturi motyvacijos nuotoliniam darbui savo namų erdvėje, kurį vertina kaip socialinę izoliaciją didinantį veiksnį. Vyresnės kartos neįgalūs asmenys pozityviau žvelgia į nuotolinio darbo namuose galimybes. Be to, jie pastebi dabartiniu metu

- esantį geresnį viešųjų erdvių fizinės aplinkos pritaikymą. Tokią skirtingą gyvenamos erdvės interpretaciją sąlygoja vyresniųjų įgyta sunkios socialinės situacijos sovietiniu laikotarpiu patirtis, kurios neturi jaunesnieji.
- 9. Judėjimo negalią turinčių ir neturinčių visuomenės narių socialinėse sąveikose galima konstatuoti esant intersubjektyvaus (abipusio motyvacinio) supratimo trūkumą. Jis kyla iš skirtingai suformuotų tipizacijų ir interpretacinių schemų, kuriomis vadovaujasi šių grupių nariai. Minėtas supratimo trūkumas pasireiškia praeivių neprašomos išmaldos davimu neįgaliojo vežimėlyje sėdintiems žmonėms, atviro gailesčio rodymu ar jo išsakymu, įkyriu žiūrėjimu ir panašiais jiems nepageidaujamais veiksmais. Tai rodo, kad visuomenė nėra susipažinusi su fiziškai neįgalių asmenų išgyvenama socialine tikrove. Dėl šio nepažinimo socialinių sąveikų metu neįgaliems visuomenės nariams primetami nelygiaverčiai santykiai: jie stigmatizuojami ir priskiriami žemesniam socialiniam statusui.
- 10. Socialinės bei sveikatos priežiūros specialistai santykiuose su neįgaliaisiais taip pat parodo savo socialinę galią. Pirminės sveikatos priežiūros įstaigose dažniausiai jie priskiriami "antrarūšiams" pacientams, kurie stokoja deramo specialistų dėmesio. Šios neįgalių žmonių reflektuotos patirtys rodo tebeegzistuojančią medicinos specialistų tendenciją vadovautis biomedicininiu ir funkcionalistiniu požiūriu į neįgalų asmenį kaip į nepagydomą ligonį ir nenaudingą visuomenės narį. Nors neįgaliesiems socialines paslaugas teikiantys darbuotojai ar jas kuruojantys specialistai turėtų gerai išmanyti žmonių su judėjimo negalia gyvenimo specifiką bei teikti jiems kompetentingą pagalbą, bet daugeliu atvejų patys neįgalieji tvirtina, kad šie specialistai tokių savybių neturi, o socialinės sąveikos pobūdis su jais nepriimtinas.

## Scientific publications on the topic of the dissertation:

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- 2. Viluckienė, J. 2008. "Iškūnyta" socialinio modelio negalios samprata", *Filosofija*, *Sociologija* 19 (4): 45–52. ISSN 0235-7186.

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- 4. Viluckienė, J. Opposition of Disability Conceptions from the Sociological Point of View. *International Conference "Baltic Readings VIII: The World Economic Crisis and Its Social Eventualities"*. Vilnius, 6 December 2008.

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