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Rasa

GENIENĖ

# Development and provision of social services to persons with psychosocial disabilities in the perspective of social care reform

**SUMMARY OF DOCTORAL DISSERTATION**

Social Sciences,

Sociology (S 005)

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VILNIAUS UNIVERSITETAS

Rasa

GENIENĖ

Socialinių paslaugų vystymas ir  
teikimas psichosocialinę negalią  
turintiems asmenims stacionarių  
globos institucijų pertvarkos  
perspektyvoje

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# 1. INTRODUCTION

Every person, irrespective of their disability, has the right to live independently and exist in a community, to be a part of it, but the practical implementation of these rights still lacks a clear divide and understanding of the meanings of declared rights behind their names. Although disability policy is a horizontal issue of public policy, its practical formulation and implementation is mostly attributed to the social security sector. What can be the results of resolving complex, interdisciplinary and multidisciplinary issues if they are resolved within the competence of only one of the ministries?

In Central and Eastern Europe, the conduct of people with disabilities has been characterized by the principles of segregation and stigmatization (Rasell and Iarskaia-Smirniova, 2013). By echoing the communist model of disability policy implementation based on constraint and isolation (Phillips, 2009), many countries in the Eastern Bloc placed people with disabilities in remote workshops and residential institutions. Disability was identified with inability to work, and a person's functioning was assessed according to medical criteria. According to prof. Jonas Ruškus, the representative of Lithuania in the UN Committee on the Rights of Persons with Disabilities, the ratification of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol (hereinafter - the Convention) *“becomes a vector for the policy of people with disability”* in the country, which obliges *“countries to free themselves from the concept of paternalistic disability and implement the concept grounded by human rights: dignity and freedoms. However, people with disabilities are still objects of care, pity and concern, and other people decide for them, opportunities for them are small to decide for themselves about their lives, to be independent individuals of their own destiny”*(2020, para. 3). Over a million people with disabilities in Europe and more than six thousand of them in Lithuania live in inpatient care institutions that violate human rights and freedoms.

Since Lithuania ratified the Convention in 2010, institutional care for people with disabilities has been one of the most criticized and debated topics in disability policy. The historical “trail” embracing communist mentality and physical material culture is like a living example of the lives of people with disabilities of the last century. The system of inpatient care is considered by some scholars and public figures to be one of the last bastions of the Soviet era (“Psichikos sveikatos perspektyvos“ (Mental Health Perspectives), 2015, p. 20). An analysis to the transformation of social care policies for people with disabilities shows that it is still strongly determined by the experience of communist perception. *“Different forms of care for people with disabilities, including charitable and patronising attitudes and their placement in care institutions, have created institutional sanctuaries for people with disabilities”* (Ruškus, 2017, p. 117). These “sanctuaries” reflect not only the real experience of people with disabilities, but also the public attitude. Such a critical view of the social phenomenon under discussion is quite static and unchanging, and it is obvious as it is about the lives of thousands of people and thousands more with a prospects of such life. The reality of recent years - human rights violations (illegal restriction of personal freedom in Skemai Social Care Home<sup>1</sup>), the global Covid-19 pandemic crisis, which revealed that about half of the world’s deaths are recorded in health care and care institutions, while the residents of care homes face double constraints compared to the rest of society, the resistance of Lithuanian cities and towns (Žiežmariai, Rokiškis, Marijampolė, Kretinga, Šakiai, Vievis, etc.) to the neighbourhood of people with

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<sup>1</sup> In September 2020, the representatives of the Human Rights Bureau of the Seimas Ombudsman’s Office, during an inspection at the Skemai Social Care Home, found a man with a severe disability locked behind installed bars in one of the premises. This event was widely publicized in media, e.g. <https://www.lrt.lt/tema/skemu-socialines-globos-namai>

disabilities<sup>2</sup> - revealed that not only the current but also the newly formed social care system faces various different problems that affect both the life of an individual and social work professionals dealing with them, social policy makers and its implementers, as well as society itself.

On 14 February 2014, Lithuania approved the “Action Plan for the Transition from Institutional Care to Services Provided in Families and Communities for Children with Disabilities and Children Left Without Parental Care of 2014-2023” (Transformation action plan), which fundamentally challenges the transformation of the domestic social policy from an institutional and paternalistic model to a communal and empowering one. This legislation is a policy imperative and, although its ambitions are not radical, i.e. country-wide; it provides concrete actions and indicators to measure some change in disability policy and to provide a basis for further action.

The most debated topics, and at the same time the counter-arguments of critics of the disability policy system in the field of deinstitutionalisation, are the following: lack of political will, inaction of municipalities, exclusion of the NGO sector, autonomy of care institutions, non-participation of people with disabilities and creation of new institutions. The relationship among different levels of these participants is often characterized by the “hot potato” principle, where responsibilities are transferred “from one hand to the other”. In a broad sense, deinstitutionalisation is not just a matter of social policy, as the implementation and effectiveness of community services requires cooperation among social, health and education and all other sectors, otherwise deinstitutionalisation can turn into transinstitutionalization, which means *relocating* people with disabilities to a different

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<sup>2</sup> In summer of 2019, the Žiezmariai community opposed the construction of the planned group living homes for people with disabilities in their community. An analogous resistance of communities occurred in other communities across the country. These events were widely presented in media (television, radio, dailies).



residential infrastructure, yet without other components of community services: personal health care, employment, education, political, cultural and other services necessary for a person. Thus, there is quite a number of participants in this “game”, therefore the transfer of responsibility or assigning it to only one of the participants will not create preconditions for the implementation of deinstitutionalization, therefore it is necessary to assess the preparedness, motivation and necessary contribution of each participant to institutional care transformation processes.

The aim of this work is to deconstruct the process of transformation of social care policy for people with disabilities in the context of deinstitutionalisation by researching the interaction of transformation participants in creating the content of community services and their interface with human rights.

### 1.1. Novelty of the dissertation

In Lithuania, deinstitutionalisation (DeI) is not perceived as a scientific problem subject to research, but rather as a social policy task that needs to be implemented or a problem that needs to be solved. Even individual researchers, who have been researching certain aspects of DeI for more than a decade, are also actively involved in the activities of NGOs of disability or human rights (e.g. Dainius Pūras, Jonas Ruškus, Eglė Šumskienė). They express themselves more in the public sphere as disability rights activists than as representatives of the academic sector. In 1989, the children’s psychiatrist D. Pūras saw the need for strong leadership in disability policy transformation in Lithuania, but as a representative of the academic community, he understood its limitation, so he approached parents raising children with mental disorders and encouraged them to establish a non-governmental organization. J. Ruškus became the Lithuanian representative of the UN Committee on the Rights of Persons with Disabilities. E. Šumskienė has been active for a number of years in the

non-governmental organization “Psichikos sveikatos perspektyvos“ (Mental Health Perspectives), which conducted the research on human rights violations in inpatient care institutions. This initiative was a kind of “prototype” of the position of leading researchers, who soon realized that by limiting themselves to academic work, they would not be able to achieve a breakthrough in shaping a new disability policy. Therefore, disability and human rights advocacy has become one of the main activities of scholars. Ironically, according to D. Pūras (2019), *“the failure in the field of deinstitutionalisation has so far been made public only by non-governmental organizations that have formed the coalition “Psichikos sveikata 2030 (Mental Health 2030). However, their voice is not enough, it can simply be ignored, which is done”* (para. 10). The research of Lithuanian scientists (presented in more detail in the part of the scope of research of the topic) includes different elements of DeI, therefore the scope of research of the DeI topic in Lithuania itself remains fragmented. The results of the research mainly reveal: the impact of DeI measures on different groups (people with disabilities, social service workers); factors of institutional resilience to change; different aspects of the field of social work (quality of services).

Lithuanian scholars consider disability, human rights, as well as deinstitutionalization discourse to be hosted by non-governmental organizations and media. On the other hand, politicians are also involved in the discourse of deinstitutionalisation by preparing official reports on its implementation. The gap in the academic discourse in the deinstitutionalisation of disability policy in Lithuania was identified by Šumskienė and Orlova (2014). Consequently, the complex task of social policy requires a science-based solution, but perhaps the scientific problem was or has been solved in other post-communist states?

In 2018, the author of the paper, together with the supervisor Eglė Šumskienė and Violeta Gevorgianienė, analyzed scientific

articles from post-communist countries<sup>3</sup> in order to study the discourse of disability and the application of the principles of the Convention in them. The analysis revealed that the perspective of the Convention is rarely used in academic discourse. Although scholars support the idea of inclusion of people with disabilities, the perspective is narrow, fragmented and does not cover the core idea of the Convention on the full realization of individual rights, which includes both independent living and deinstitutionalisation. Researchers have mainly aimed to discuss various aspects of the lives of people with disabilities, but without relating them to the provisions of the Convention. Only about 10% of scientific articles examined focused on the implementation of the provisions of the Convention. According to Primeau, Bowers, and Harrison (2013), without addressing the issues of implementation of the rights of people with disabilities, deinstitutionalization often becomes transinstitutionalization in post-communist countries.

According to Jonas Ruškus (2021), the authorities base the failed DeI process on the negative attitudes of society towards people with disabilities, yet emphasizes that *“attitudes towards people with disabilities will remain humiliating and degrading unless discriminatory laws and regulations restricting or even depriving people with disabilities of freedom and dignity, civil and political rights on the grounds of disability are changed”*(para 14). Thus, societal attitudes and the legislative level become interdependent. Deinstitutionalization first of all means process, therefore, to extend J. Ruškus’ idea on the flaws of social policy, the unfolding and detailing of the complex process would allow to study the main gaps of DeI. Rasell and Iarskaia-Smirnova (2013) summarize that the situation of people with disabilities in post-communist countries is little known to both scholars and the general public, while communist legacies of

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<sup>3</sup> Selected articles covered academic discourses in Lithuania, Ukraine, Belarus, Latvia, Estonia, Slovenia, Bulgaria and Russia. A total of 145 articles covering the period 2007-2017 were analyzed, taking into account the fact that the Convention appeared in 2006.

control, segregation, and stigma are irreplaceable due to unstable policies and the context of ambivalent civil society. Such dependence presupposes and only once again justifies the complexity of the phenomenon, the understanding of which requires a complex solution offered by the author of this paper.

### **The scope of research of the topic**

*Abroad.* Sociological research in post-communist countries became popular in about 2000. Until then, academic interest in disability in Eastern Europe and the former Soviet Union was fragmented and limited to the research of individual scholars, mostly historians. The Eastern and Western worlds were separated due to linguistic challenges, making it extremely difficult for researchers in post-communist countries to promote their research in the foreign science market. Despite globalization, the scientific discourse of today is dominated by research by local post-communist scholars. Luse and Kamerade (2014) examined the situation of psychiatric patients in communist and post-communist Latvia, Gabor (2014; 2019) - in Hungary, and Mladenov (2014; 2015; 2019; 2020) - in Bulgaria studied the implementation of the Convention; Phillips (2014) studied the situation of disability and citizenship in post-communist Ukraine. In Bosnia and Herzegovina, Bacirevic (2014) researched the role of non-governmental organizations in achieving the integration of people with disabilities. In Armenia, Azerbaijan and Georgia, Shmitd (2014) explored the DeI challenges in child care. One of the most famous sociologists of the post-communist society conducting research in the field of deinstitutionalisation, disability studies and in the field of alternative research for institutional care, is considered to be the sociologist Teodor Mladenov. The course of deinstitutionalisation in post-communist societies is also being studied by sociologist Darja Zaviršek. The generality of the research conducted by the above authors is the aim to reveal the discrepancies between deinstitutionalization and the policy implemented under it. Transformation of deinstitutionalization as a the global process and

values into glocalization (application and adaptation of global trends according to domestic contexts) was explored by An and Kulmala (2020). The situation of human rights for people with disabilities in post-communist countries has been studied by Phillips (2009; 2013). However, such research reflects more on the outcome of a policy (and often an unsuccessful one) than on the implementation of its process, on which the problematic aspects of DeI depend.

*In Lithuania.* Manifestations of deinstitutionalization research in Lithuania can be found since 2005, when non-governmental organizations carried out human rights monitoring in closed mental health care and care institutions. More extensive research on human rights monitoring and implementation of the Convention was conducted in 2014, 2015 (Public Institution Psichikos sveikatos perspektyvos (Mental Health Perspectives) and in 2018 (Levickaitė and Mataitytė - Diržienė). The mental health care system was studied by Šumskienė and Pūras (2012, 2014). Genienė and Šumskienė (2016) analyzed the transformation process in the perspective of the theory of institutionalism. Different aspects of DeI and community services were also explored: in 2005, Germanavičius wrote about employment with assistance, in 2018, Griciūtė and Senkevičiūtė - Doviltė examined the motivation of employees working in social care homes by participating in the transformation process; Gudelytė and Ruškus (2019) wrote about the importance of support in decision making as a component of DeI implementation. In 2019, BGI Consulting UAB together with Contextus UAB, at the request of the Ministry of Social Security and Labour (MoSSL), carried out the assessment of the first stage of the transformation, which examines the changes in the quality of life of people and employees after moving to a group living home and sheltered housing. Ruškus (2019) and Genienė (2020) examined the Covid-19 pandemic as a stimulus for DeI implementation.

By summarizing the research conducted in post-communist countries, including Lithuania, it can be stated that the scope of research of DeI results is fragmentary, covering different components

of DeI and significance for separate social groups (e.g. people with disabilities, social service workers, NGOs). Although the studies examine individual aspects of DeI, their diversity justifies the complexity of DeI. The results of the research are mostly employed to substantiate the need for DeI or to discuss the results, however, the causal links between the problems underlying the broader and complex research have not been established in this area yet. There is a lack of research to explain why DeI results are considered unsuccessful. Where are the causes of the DeI consequences identified by scientists? On the other hand, as mentioned above, the results of DeI are interpreted by unstable policies or discriminatory laws, but such generalizations do not offer solutions to the problem, and do not investigate its causes.

### **Novelty and significance of the paper**

In this paper it is assumed that the success of DeI policy implementation depends not only on its formers, but also on the institutions responsible for its implementation, therefore, the measures of the transformation being developed may be ineffective if there are no equal responsibilities among the individual transformation participants. Both Lithuanian and foreign scientific discourse is dominated by the fragmented DeI research or its results, the impact on the participation of people with disabilities in society, however, there are no research revealing the complexity of the DeI process, ways in which the different participants in the transformation process interact, with the above-mentioned problems of structural discrimination and unsustainable policy solutions. With the help of the agency theory, which explains the relationship among organizations in which one party is called “principal”, sets tasks, and in which the other party, called the “agent,” executes or makes decisions on behalf of the principal, the DeI process failures and structural barriers for agents involved are analyzed. The assumptions of ecological systems theory were used for the systematic perception of transformation allowing to evaluate the analyzed phenomenon systematically and consistently.

The strength of socio-ecological models is that they emphasize the existence of relationships among levels and that certain combinations of levels can have a greater impact (Scholmerich and Kawachi, 2016). One of the main reasons why the system is stagnant and difficult to implement is the lack of involvement of system participants and the lack of awareness of the importance of the whole ecological system (Gocheva, Lu, Li, Bratanova-Doncheva and Chipev, 2019). The matching of the two theories allows to investigate both the systemic levels at which the main transformation disturbances occur and to explain the causes of these disturbances.

One of the main novelties of this paper is the complexity of the study, combining different research strategies, applying expert survey, document analysis and case study, and the involvement of all participants in the transformation context, revealing the DeI process phenomenon from different perspectives and standpoints. Empirical research is usually performed by analyzing a part of the researched phenomenon, but in this case the phenomenon under research is complex, covering all interested groups of the transformation process, therefore the work performed allows to analyze the transformation topic in a consistent manner.

The results of this paper have high applicable value. They can be useful in covering all interferences and barriers in the transformation process, the identification and overcoming of which would contribute to catalysing the transformation process and the development of community services. The results of this work can also be applied as a means of drawing the attention of the responsible authorities to their own role in the successful implementation of the transformation. Given that the transformation of institutional care is one of the priority areas for action, and in the new 2021-2027 period of support from the EU Structural Funds, the results of this work can be used as a tool enabling to better prepare and address issues needing much more attention at the planning stage.

## 1.2. Aim and objectives of the dissertation

**The research problem** is lack of knowledge on how the process of deinstitutionalisation can be deconstructed to grasp the causes of problems during deinstitutionalization. Without having empirical data on challenges faced during the deinstitutionalization process, we will not be able to overcome barriers to institutional care transformation and reduce the negative impact it may have on PWD welfare, especially to solve the problems of transinstitutionalization. Based on agency and ecological systems theory, dissertation aims to investigate the interaction among the participants in the transformation, how the content of community services is created during it and its connections with the implementation of human rights and independent living.

**The aim of the dissertation:** to investigate how the process of transformation of social care institutions transforms, develops and provides services to persons with psychosocial disabilities.

**The object of the research:** the process of social services development and provision in the perspective of social care reform.

**The objectives:**

1. To study the model of the institutional framework for the implementation of the institutional care reform;
2. To discuss the peculiarities of the interaction of the participants implementing the institutional care reform;
3. Investigate how the development of reform measures at the legal (regulatory) level operates at the practical (implementable) level;
4. To analyze the peculiarities of community services development.



### 1.3. Structure of the dissertation

The first chapter of the dissertation “Deinstitutionalization in the Perspective of Ecological Systems Theory and Agency Theory” presents the advantages of selected theories in analyzing the researched phenomenon and the combination of tools of these theories, the use of which allows to analyze the process of deinstitutionalisation from all angles and different perspectives. In the implementation of DeI community services alternative to institutional care are developed. The final quality of the result depends on both the components - the content and the effective implementation – the process. In this paper, the ecological systems theory is used for the analysis of DeI content, which allows to study the position of the transformation participants in the process, their environment and their interaction with other transformation participants. To study the efficiency of the DeI process, the agency theory was selected, which allows to analyze the factors determining the actions or inactions of the participants in the transformation, the existence of which affects the quality of the developed services. To put it plainly, if we answer the question of what we need to improve, we need to know how to improve it as well.

The second chapter of the dissertation presents the evolution of disability models - from medical to human rights. The interpretation of the models contributes to the content of the community services explored in the empirical part, i.e. allows to identify the model according to which alternative services for institutional care are developed. This chapter also introduces the deconstruction of institutionalization, which means that when creating community-based services, we need to know the attributes of institutions. This chapter focuses more on E. Goffman’s (1961) concept of totalitarian institutions and stigma and N. Fraser’s (1996) interpretation of social justice theory. Being aware of the main attributes of institutions, stigma-building practices and processes of ensuring social justice, the

research part can be used to examine how these factors are ensured or how they are abandoned in the development of community service practices. Further in this part, the concept of deinstitutionalisation is interpreted, its different meanings of usage and the consequences arising from it, the Convention on the Rights of Persons with Disabilities are presented, and its effectiveness is assured. This section also presents the author's research with the analysis of the official and shadow reports of the post-Soviet Convention on the Rights of Persons with Disabilities.

The third chapter of the dissertation presents the participants of the institutional care transformation: the Ministry of Social Security and Labor (MoSSL), municipalities, non-governmental organizations (NGOs), social care institutions and transformation experts<sup>4</sup>. The participants in the transformation are described on the basis of the nationally regulated legal framework, i.e. describes their main activities, accountability and subordination. They are also analyzed on the basis of scientific articles and data that reveal the peculiarities of their interaction with the external environment.

The fourth chapter of the dissertation is intended for the presentation of community services. It presents alternatives to institutional care related to accommodation created during the transformation: community services related to accommodation: group and independent living houses, sheltered housing. Non-accommodation services aimed at preventing access to institutional care are also introduced. These include services such as personal assistance, a temporary respite for relatives of people with disabilities, case management and sheltered workshops. More attention is paid to the description of group living homes and sheltered workshops as services replicating the pattern of separation and segregation.

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<sup>4</sup> A transformation expert is a person hired to consult transformation participants on the implementation of transformation measures. The transformation expert is also a participant in the transformation.

In the fifth chapter, the author presents the methodology of the research in detail. In the sixth chapter, the results of the research are shown. In the seventh chapter, the author discusses the links between the research results and disability assessment models, E. Goffman's concept of stigma and N. Fraser's theory of social justice. At the end of the dissertation, the conclusions of the work, recommendations for social policy makers and its implementers and other researchers are presented. The attachments also provide information about the dissertation in an easy-to-read format.

## 2. METHODOLOGICAL PROVISION OF THE RESEARCH

To achieve the aim and objectives of the research, a three-stage study was performed, combining quantitative and qualitative research methods. During the research, expert opinions were analyzed, document analysis and a case study were performed. The general scheme of the research methodology is based on the ideas of the agency and ecological systems theories on the complex operation of the system.

Institutional care transformation actions and community service development were studied as a process of interaction of different groups of society - transformation participants, micro-systems - interactions, which form a certain system, the process determining the respective content and impact at various system levels: the micro, meso, exo and macro subsystems. The ongoing process changes the chrono-system on a time scale, which describes the change in time of a particular system, i.e. expresses change. Because actions to transform institutional care and develop community-based services in society are often fragmented, i.e. different institutions, communities, media play different roles, the application of qualitative and quantitative methods allows to consider the research process as homogeneous. The combination of different research methods also makes it possible to overcome the shortcomings of the application of

individual methods; to collect diverse and rich material about the analyzed social phenomenon; to base the results of the study on different data sources.

The study looked at the transformation process from different perspectives, examining the transformation both in a broad context (macro and exo systems) that includes planning and coordination stages, and in the particular case, to view transformation processes “live” in a specific community (meso and micro levels).

### **The first stage of empirical research**

**The aim** of the first stage of the research was to analyze the course of the transformation through the peculiarities of the involvement of various participants in the transformation process.

The success of institutional care transformation is inseparable from the partnership, active involvement and participation of different transformation participants in the DeI process, as at this stage different participants become interdependent, while the DeI process itself depends on transformation participants, therefore, by examining the factors of participation of these groups in the transformation process, the results of the transformation can also be examined.

#### **Objectives** of the first research stage:

1.1. To analyze the peculiarities of the involvement of the transformation participants in the planning, course and evaluation of the process.

1.2. Investigate the interrelationships and interactions of different participants in the transformation process.

1.3. Reveal the course of the transformation, the results achieved and the main interferences from the perspective of the participants.

When planning the empirical study of this work, it was decided to analyze the opinions of the representatives of the transformation participants working in the field of transformation - experts - on the

effectiveness of the transformation. Expert surveys are particularly useful in assessing policy change and explaining issues arising in the process of change (Maestas, 2016; Levick and Olavarria-Gambi, 2020). According to Ericsson, Charness, Feltovich and Hoffman (2006), expertise is acquired in two ways. In the first case, expertise arises from the practical ownership of communities, therefore, in this respect, expertise is socially constructed - means of thinking are jointly developed in social groups, which together define and gain experience in a particular field. In the second case, expertise arises from the conscious developing of an expert's knowledge and the accumulation of experience in a broad context, i.e. without relying solely on the expert's work experience. In this study, subjects are classified as experts because of the peculiarities of expert knowledge.

First of all, they represent a particular social group or organization involved in the implementation of the transformation, so they are participants in the transformation or can be identified as representatives of the participants in the transformation.

Second, experts, as participants in the transformation, implement certain measures and can assess the (in) effectiveness of these measures, identify problem areas or suggest solutions.

Third, in a broad sense, experts, constantly being in the "medium" of transformation (i.e. in the ecological system), can assess the (in) performance of other participants in the transformation, provide an opinion on their strengths and weaknesses.

Fourth, acting at a particular level of the ecological system, the phenomenon under analysis can be assessed at various levels or breakdown of the system.

Fifth, experts play the role of a principal or an effector (agent) in the implementation of specific measures, so their experience is crucial in revealing the specifics of the transformation process.

As mentioned before, the actors in the transformation represent different sectors, institutions and groups in society, therefore their views may differ due to the fragmentation of representation,

opportunism, practical experience and expertise. It is also important to emphasize that such qualitative approach aiming at scientific objectivity is often criticized for the subjectivity of experts, both in terms of personal opinion and in terms of feelings and worldviews (Kardelis, 2005). This is also explained by the ecological systems theory, which emphasizes the dependence and integrity of individual parts of the system, i.e. transformation participants are influenced by macro-system values, the goals of the organization within the exo-system, the meso-system's experience in communicating with other transformation participants, and the roles within the micro-system that they perform directly. The Delphi method was chosen in response to the identified problem areas and to reach a general consensus and refine the problems. The Delphi method is used when the aim is to reach a unanimous opinion of experts in the assessment of complex phenomena, while the obtained results allow to predict the effectiveness of the phenomenon under research in time perspective, and hence in the chrono-system. Researchers analyzing the DeI experience note that the first and main problem in implementing DeI is the lack of a general agreement (consensus) from the idea of DeI itself to concrete measures (Scherl and Macht, 1979; Talbot, 2004). The uniqueness of the Delphi method is that experts are given the opportunity to share their opinions and ideas individually and in a group, allowing them to avoid confrontation with different opinions (Okoli and Powlowski, 2004). Constructive discourse was also created by this way of choosing the research, and its stages help to achieve a systematic analysis of the connections between the text (the opinion expressed by an expert) and its social conditions, ideologies and power relations. Interpretations are always dynamic and open to new information and new contexts (Morkevičius, Telešienė and Žvaliauskas, 2008), therefore disclosing the opinion of other experts allows rethinking arguments, confirming or denying, as well as learning new information.

The application of this approach in the context of social policy transformations is little examined, but given that DeI assessments are often unidirectional, reflecting the views of a particular participant, sector or community, this approach is authentic as it helps different groups to participate in the overall transformation assessment, to get aware of different and substantiate personal opinions.

**Selection of experts and characteristics of the subjects:** As the study is aimed at the analysis of different participants (agents) in the transformation, experts were selected according to the five main groups of transformation participants identified by the researcher: MoSSL, transformation experts, municipalities, NGOs, social care institutions. Targeted, criterion-based selection was used to select experts from these groups based on the following criteria:

- 1) An expert participates in the working groups for the management and / or cross-institutional monitoring of the transformation action plan.
- 2) An expert represents the group of transformation participants, and their practical activities are directly related to the implementation of the transformation measures.
- 3) An expert, with the exception of MoSSL, is a member of a national association representing a particular participant in the transformation.

The selection of experts was carried out in accordance with the principle of proportionality, i.e. in order to balance the different participants in the transformation. 18 experts agreed to participate in the study: 3 - from MoSSL, 3 - transformation experts, 4 - from municipalities, 4 - from NGOs and 4 - representatives of social care institutions. The selected experts are managers or representatives of organizations working directly in the field of institutional care transformation. Experts representing each participant in the transformation were selected in a consistent manner to ensure representation at both national and regional levels, in order to maximize the scope of the study. 39% (7 out of 18%) participants are

representatives of the cross-institutional transformation monitoring group.

The Delphi study was implemented in three phases. In the first phase of the study, the experts answered semi-structured questions. 5 study experts completed the questionnaire in writing, and 13 experts were interviewed. Interview data were transcribed. The experts' opinions were summarized and assigned to certain thematic categories according to the objectives of the study. In the first stage of the research, 10 topics were identified, to which expert opinions were assigned. A total of 116 statements were received, which were re-evaluated by the experts in the subsequent stages of the study (second and third), giving them meaningful values.

### **The second stage of empirical research**

**The aim** of the second stage of the research was to analyze the process of transition from institutional care to the development of family and community services.

**Objectives** of the second stage of the research:

2.1. To analyze the activities of external institutionalized working groups participating in the implementation of the transformation action plan.

2.2. To analyze the content of community service projects and to review the change of normative legal acts regulating the development of community services in 2012-2020.

2.3. To assess the compliance of municipal social service plans with the transformation measures implemented in the country.

The process of service development is perceived in this paper as political factors influencing the development of social and community services. These factors include criticisms of institutionalized working groups, legislation regulating transformation and the actual development of services.



The document analysis method was used to analyze the service development process. Atkinson and Coffey (1997) refer to documents as “social facts” (p. 47). Like other research analysis methods, documents are analyzed for the analysis and interpretation of data in order to gain meaning, obtain understanding, and develop empirical knowledge (Bowen, 2009). Documents can provide data on the context in which a phenomenon is being researched, and their analysis provides an opportunity to monitor change and development. Documents can be analyzed as a way to verify conclusions or sustain evidence from other sources. Official documents are usually strictly structured, template-based, however, they can be used to examine relationships, problems, situations. For example, interpretations of situations and events, views, opinions, experiences, etc. of the members of the working groups are recorded in the protocols of the working groups.

A three-part research was planned for the consistent implementation of the aim, taking into account the objectives of the study. Firstly, the research focuses on external institutionalized working groups, which have the right to respond to the ongoing integration processes of people with disabilities in the country in accordance with the procedure established by law. Secondly, it was aimed to examine the compatibility of the transformation measures and to review the changes in the regulatory acts and the compliance with the transformation objectives. Third, an analysis of the content of municipal social service plans was carried out allowing to assess the practical implementation of transformation measures related to the development of community services. The objectives of the research presupposed the main sources of information used for the analysis of the documents:

- Reports of selected working groups used to examine the activities of external institutionalized working groups;
- Normative legal acts regulating the directions of the policies of social and community services, peculiarities

of their organization and provision were selected for studying the implementation of the transformation objectives, as well as reports on the implementation of the transformation measures (projects);

- The development of community services on a practical level was studied by analyzing municipal social service plans, as well as information was collected in reports on the implementation of transformation measures.

### **The third stage of empirical research**

**The aim** of the third phase of the research was to reveal how the transformation process took place in a particular community.

The following **objectives** were formulated to achieve this aim:

3.1. To analyze the communication of Marijampolė municipality's transformation participants and community members when planning institutional care transformation actions.

3.2. To analyze the community's responses to transformation, issues raised, and feedback received.

3.3. To analyze the role of transformation participants in the context of the case of Marijampolė municipality.

A case study was chosen to achieve the aim of the research. A case study is a research strategy that involves a detailed, in-depth study of one or more cases based on as many sources of social information as possible and applying the widest possible range of social research methods (Morkevičius, Telešienė and Žvaliauskas, 2008, p. 28). According to the aim of the case study, an instrumental case study was performed in this research, where the aim of a researcher is to analyse a certain broader problem, but the case is chosen here as illustrating the expression of the problem. The case study is used when the researcher aims to identify all factors that may influence the phenomenon under research (Rashid, Rashid, Warraich, Sabir and Waseem, 2019).

The community of Marijampolė municipality was chosen for the implementation of the case study for several important reasons. First of all, in Marijampolė district, with regard to the plans of all municipalities participating in the transformation, it is planned to establish the biggest number of group living homes. Second, it is expected that a large number of group homes planned to be built will affect a significant proportion of community members (i.e. they will settle in their neighbourhood).

Several data collection methods have been chosen to implement this research strategy: observation, analysis of documents and audiovisual material.

**Observation.** According to Rupšienė (2007, p. 109), by observing a researcher perceives the diversity of interactions, i.e. what the informants do not talk about (avoiding or simply not perceiving), they form a comprehensive picture of the researched problem. Observation is used to learn about group relationships or the course of conflicts. According to the typology of observation, informal observation, also called unstructured, or exploratory observation was applied. In this case, the researcher does not have specific observation units, and the research can be described as a trip to an unknown place where every detail may be important. According to the researcher's participation criteria, the author of the paper was both a participant in the observed group and an observer of the situation from the outside. This choice of role was determined by the complexity of the situation under research, when changes in the community take place both directly, e.g. community meetings, and indirectly, e.g. via media. In this case, both internal and external observations were performed. The role of the observer as a participant was chosen for the internal observation within the group. Internal observation means attending MoSSL, municipal and community meetings. Under the criterion of openness/secretcy, the researcher participated as a covert observer when a particular community was unaware of being observed. It is said that observers tend to change their role to some extent when they are

aware of being observed, so in the case of the covert observation, the community behaves more naturally. Sometimes such studies pose a risk of a “cheating problem,” but in this case, this risk is considered to be absolutely minimal as the observed phenomenon involves a relevant context of community transformation that is public to community members and other participants, e.g. meetings with the community.

The analysis of documents, which is presented in more detail in the second stage of this research, covered the analysis of the minutes of the municipal council and official letters (appeals, correspondence) among the municipality, the community and MoSSL.

The analysis of audiovisual material was applied to the study of spoken texts, images, photographs, pictures, video and audio recordings. This material was collected from media. In order for the researcher to record important events in time without missing tem, as noted in the research protocol, Marijampolė municipality newspapers were periodically reviewed, Facebook accounts of Marijampolė municipality administration employees, council members, community, and a Seimas (Parliament) member were followed.

**The course of the research:** This study, in terms of time, took the longest time and lasted longer than expected, as during the dissertation preparation, active resistance of the community to the transformation processes began. The emerging resistance has become an important component of the research as disability assessment models, stigmas, and other important elements of the process have emerged. At the beginning of the research, various meetings were organized by the transformation coordinator (“principal” - MoSSL) and by the effectors of the transformation (“agents” - municipalities, NGOs and social care institutions). Later, the monitoring process was carried out on the principle of a “snowball”, when units of statistical population are to be included in the survey and the inclusion takes place through those already participating in the survey (Rupšienė, 2007). The “snowball” selection may sometimes be the only way to

reach the units of statistical population. This selection is special in that each informant already participating in the research can recommend units to the researcher, introduce them and include in the study other informants who belong to a relatively limited but unique and meaningful population that is difficult for the researcher to reach and about which the researcher has little or no information (Rupšienė, 2007). In the case of this study, the application of the observation method to the researcher “prompted” critical sources of information that the researcher did not even foresee at the beginning, e.g. the position of the members of the municipal council.

### 3. CONCEPTUALIZATION OF THE PROCESS OF SOCIAL CARE TRANSFORMATION IN THE PERSPECTIVE OF DEINSTITUTIONALIZATION

#### 3.1. Analysis of institutional care transformation: expert perspective

***Force majeure* transformation trends.** The results of deinstitutionalization depend on the interaction between the participants in the transformation and the content created during it, which is decisive with regard to people with disabilities. The Delphi study revealed that there are certain forces of *force majeure* in the transformation, which are independent of the actions of the main participants in the transformation (MoSSL, municipalities, NGOs and social care institutions). This category can be characterized as the influence of individual policy participants on the act/omission of the transformation, the problems of financing social care, the lack of political leadership.

Experts came to the unanimous conclusion that the financing of social care, i.e. the state’s targeted grants to municipal budgets, program the conditions of a person’s access to institutions, as it becomes a free alternative and a way to problem solving for the

municipality. This gap resulted from the flaws of the legal framework. According to the Law on Social Services, social care for persons with disabilities is financed from municipal budgets, however for persons who were admitted to social care institutions before 2007, social care is paid from the state budget. The same law stipulates that social care for persons with severe disabilities is financed from the state budget's special targeted grants to municipal budgets.

One of the most highlighted obstacles to the implementation of the transformation is the lack of political leadership. MoSSL implements the state social security policy, however the need for transformation is not dictated by national policy, but rather by international obligations, therefore MoSSL constantly and at various levels has to prove the need for transformation. Experts in the research unanimously criticized the excessive and unconstructive attention of politicians to the cost analysis of transformation and the maintenance of the new system, i.e. that the country's top politicians often emphasize and criticize the costly maintenance of the new system.

The lack of political leadership is also related to the "face" of the transformation, i.e. the absence of a specific person associated with the transformation. Experts share the view that a leader in the implementation of the transformation who is not afraid to speak publicly about the transformation and to represent the rights and interests of people with disabilities, is missing a lot. This may be related both to the fear of losing popularity due to the stigmatization of the target group represented and to other processes. As the experts have pointed out, the transformation for some politicians is an obstacle to pursuing a political career, as the voices of residents, employees and relatives of one large institution have a decisive influence on a person's entry into the Seimas, therefore, it is beneficial to have supporters in one large social care home. In this case, MoSSL, as an institution, is separate from the political trail in the Seimas, i.e. the two institutions carry out different activities, although they are

interdependent (e.g., on the implementation of the Government program).

According to Pierson (2000, p. 59), “*even small differences in political power between competing groups may have a huge impact.*” Since, in this case, care institutions become the transformer, in the prism of the agency theory, when an agent belongs to a particular interest or activity group, they may be influenced by other members of a team, which in turn directly affects the nature of participation in the institutional care transformation process.

Therefore, transformation as a process is indivisible - it involves not only particular participants in the transformation who perform certain tasks, but also politicians who may have a decisive voice in the implementation of the transformation. The transformation of care institutions lacks a particular leader who is not afraid to speak publicly about human rights’ violations in care institutions and the right of people with disabilities to live in the community. For example, the transformation of children’s care had the political support and face of the President Dalia Grybauskaitė, so this transformation, although it began with the deinstitutionalisation of care homes for people with disabilities, took place faster and with a greater success. It is important to emphasize that the President herself chose to lead on the topic of children. Thus, political leadership had contributed to solving problems within the macro-system. According to experts, the topic of disability is not as rallying, mobilizing for political leadership as children. Politicians are legislators, so the above-mentioned peripheral factors do not motivate politicians to change the legislation that programs the access of individuals to care institutions. On the other hand, the modification of the financial mechanism should be considered and modified at an early stage of the transformation, as the involvement of municipalities in the transformation seems to depend on the financial mechanism. It can only be inferred that municipalities would have been much more effectively involved in the current stage

of transformation if an effective financing model for community rather than institutional services had been enacted in the country.

**MoSSL, as a social policy maker.** In course of the Delphi study, experts were asked to evaluate the strengths and weaknesses of MoSSL in the transformation process. The experts came to the unanimous opinion that only MoSSL identifies itself with the implementation of the transformation. Although three ministries (MoSSL, the Ministries of Education, Science and Sports, and Health) are formally responsible for the implementation of the transformation, only MoSSL is actively involved in the implementation of the transformation. Endorsement of this view reveals a very important and rather unsuccessful feature of the process of institutional care transformation from the perspective of the Convention. The different activity of ministries shows the imbalance of the exo-system, when only certain parts work and others do not. This, in turn, affects a variety of micro-systems operating in the community, as, for example, health care facilities, libraries, cultural houses, schools, etc., although established by municipalities, however in a broad sense, their activities are regulated by the relevant ministry. The provisions of the Convention state that inclusion in the community can be achieved when people with disabilities have access to all services available in the community, and these must be adapted to the needs of people with disabilities. A person's daily life is inseparable from health care, education, employment, transport services, participation in political, cultural and other activities. Therefore, in addition to the three formally involved ministries, other ministries (Ministries of the Interior, Culture, Transport and Communications, and Justice) must take responsibility for implementing these provisions.

The experts also noted the risks posed by the instability of MoSSL's political leadership, which is related to terms of office, so operational priorities and perceptions of the transformation may vary. The research revealed that MoSSL, as a transformation coordinator, confronts with problems across the organization. First of all,



regulatory problems related to the lack of human resources and the peculiarities of the bureaucratic mechanism in regulating the new legislation defining community services. In addition, different units of the Ministry are responsible for the implementation of the restructuring measures, therefore the process is uncoordinated and information asymmetry emerges. Second, MoSSL experiences difficulties communicating with external participants in the transformation process, especially municipalities and NGOs. NGOs often criticize MoSSL activities, which in turn leads to distraction and sensitivity to NGOs criticism. Third, MoSSL is experiencing difficulties in its relations with the EU. The transformation is being implemented with the help of EU funds, so there are fears of setting ambitious goals, and actions that can be accounted for are planned only, however they are not implemented nationwide and do not cover the expectations of all people with disabilities.

**Independence and autonomy of self-government.** The Delphi study also analyzed the role of municipalities. The experts came to the common conclusion that the self-regulation of municipalities creates conditions for disregarding international legislation and strategic directions. The Law on Local Self-Government defines that the independent function of a municipality is the planning and provision of social services, the establishment, maintenance of social service institutions and cooperation with non-governmental organizations, and the creation of conditions for the social integration of people with disabilities living in the municipality to the community. The independent function means that in its implementation, municipalities have the freedom of initiative, adoption and implementation of decisions established by the Constitution and legislation, and are responsible for the performance of independent functions. As the results of this research have shown, all the chain parts involved in the implementation of the transformation, in which municipalities play an important role, are weak: no decisions on the provision of alternative community services are taken, no cooperation with the non-

governmental sector (inactive level of meso and exo systems) takes place. *Inter alia*, experts agree that NGOs in municipalities feel depowered, municipalities are not interested in strengthening them and making them equal partners. Communication between NGOs and municipalities is based on the principles of power, which is realized through financial mechanisms: service providing NGOs stay away from speaking out loud for fear of losing funding.

Experts feel the lack a mechanism to involve and oblige municipalities to participate in the development of community service infrastructure. One of the most effective ways of informal contracting is the moratorium adopted by MoSSL stating that in the long term it will no longer be possible to send and accommodate people with disabilities to care institutions under the Ministry.

This is one of the major ways to motivate municipalities to engage in transformation processes, however it is not an effective, inclusive and credible mechanism. In case a municipality refuses to participate in the development of the infrastructure, these functions will be taken over by the institutions subordinate to MoSSL. This fact not only justifies the power instruments available to the municipality for both MoSSL and the transformation, but also reveals the systemic shortcomings of the restructuring itself, as the granting or transfer of means to institutions subordinate to MoSSL further supports the existence of care institutions: as a legal entity at least and as the same institutional culture at most, the transformation of which is being attempted to give up during the transformation. Experts believe that, in contrast to the current situation, the initiators of the transformation should be municipalities, driven by the interest that their residents should not enter inpatient care institutions. However, the current legal framework does not oblige municipalities to demonstrate concern for the quality of care services or to take responsibility for its residents who moved to a care home in another municipality. It is therefore paradoxical that MoSSL institutions are establishing a community service infrastructure in an effort to bring municipal residents back

into their community. This is also strongly related to another consolidated statement by experts that, from the point of view of municipalities, people in institutional care belong to the state, by leaving out of consideration that they came from a particular municipality, city or town community. At this point, the reasons again converge on the flawed financing scheme of social services, which becomes a low-cost and handy alternative for municipalities in solving a particular person's problem. Experts note that there is no cooperation between municipalities and care institutions, which is necessary if the situation, life course, etc. of a particular person is taken care of, therefore it can be acknowledged that a person who gets into the social care system becomes a resident and concern of the state rather than of a municipality. The meso-system successfully pushes out a person with a disability into the macro-system and steers clear of readmitting them, which at the same time supports the existence of a medical assessment of the disability.

By analyzing the situation of institutional care transformation, one can also see positive changes taking place in the responsibility of a municipality. Experts note that there are cases when municipalities accommodate children with disabilities together with children without disabilities - in community children's homes, therefore it can be observed that the attitude of municipalities towards children with disabilities is gradually changing. This approach, in the opinion of experts, is related to mental health literacy and the young age of municipal politicians, as municipalities with these characteristics stand out for their better approach to institutional care transformation. Young politicians are less affected by the Soviet mentality, born and raised at a time when human rights, equality and non-discrimination are discussed more. However, such municipalities are identified as isolated cases in the domestic context.

**NGOs: from active transformation initiators to passive followers.** According to experts, NGOs were the initiators of the transformation, the "hosts" of the topic, but in the long term this role

was taken over by MoSSL. Currently, NGOs are no longer the masters of the discourse of transformation, which is partly due to fragmented involvement, opposition, displayed dissatisfaction, lack of cooperation, etc. In terms of the transformation, the decline in NGOs involvement is a huge comedown in the context of deinstitutionalisation, as the counterweight to ensuring the rights of people with disabilities diminishes over time. The research revealed opportunism among NGOs, which is based on the use of transformation resources for organizational or institutional gain. This can be explained by the different motives of NGOs to participate in the transformation - one of them is motivated by the opportunity to resolve the family situation, the second - the wish to strengthen their political influence, the third - the opportunity to earn extra money from transformation projects or different combinations of these motives. At this point, this not only creates various risks between the principal and the effector, but also distorts the image of the transformation, as NGOs are heterogeneous, different, have individual interests that may in some cases contravene long-term transformation goals. Second, experts unanimously agree that NGOs use the restructuring context as an additional resource to support their activities. According to experts, this participant in the transformation differs from other sectors involved in the transformation as the “most winning” sector. On the one hand, this is necessary and normal, as in the case of the development and quality of community services, NGOs are expected to become service providers, so it is understandable that the non-governmental sector must be one of the key players in the transformation. On the other hand, experts partly agree that NGOs are reluctant to try out new innovative services, and provide services based on long-standing experience. It is considered that this statement cannot be accepted in its entirety, in particular because no decisions have been taken during the transformation process on a mechanism for assessing the content and quality of the services provided. The

principal evaluates only quantitative (i.e. what needs to be accounted for in the EU), not qualitative indicators of service provision.

**Social care institutions: from resistance to the centre of power.** The assessment of care institutions, compared to the evaluation of other participants in the transformation, highlighted many different statements. This makes it possible to assess that care institutions, as participants in the transformation, play a very important role in the transformation process. Experts unanimously agree that some managers of social care home see the transformation of institutional care as a breakdown of large institutions into smaller ones. Unfortunately, such thinking can lead to the failure of the transformation. As the care institutions themselves were the first to establish group living homes, there is a high risk that institutional culture may be “transferred” to new homes. Experts noted that the institutional culture is felt not only inside the group living homes, but also in the very process of establishment of these homes. Group living homes (ribbon-cutting, invitations of a mayor, elder, street chairmen, celebrations) is an example of the “transfer” of institutional culture.

Experts entirely agree that the attitudes of a manager of a care home have a direct impact on the preparation of employees for the transformation. Further on, the chain sequence follows, as experts equally agree that employee attitudes affect the mindedness of people with disabilities towards the transformation. Employees are unsure about their professional future, while residents of institutions feel anxious about changing their place of residence. For these reasons, some institutions are not actively involved in the transformation. Experts acknowledge that as a manager opposes the transformation, an institution’s employees are used as a tool of resistance that is easy to manipulate, influence, and intimidate. Employee attitudes were researched back in 2012. During the study it was found that at employee level the practice of demonstrating interest in transformation was lacking, additional tasks were avoided, and the catalysis of unwanted change received reluctance. Accordingly,

information that travels “hierarchically” was passed on to residents of social care homes themselves.

Transformation experts also agree that most of the transformation of social care homes is carried out with reference of the direct instructions of MoSSL, as a founder. Although the “coercion” mechanism is not welcomed, it is observed that the tested experiences of group living change the attitudes of managers. After trying alternative services, managers no longer treat the implementation of the transformation as the liquidation of the institution, on the contrary, they see positive changes in people’s lives and become more actively involved in the transformation process. As care institutions were the first in the country to establish group living homes, these processes gave a manager of a particular institution a great deal of responsibility in deciding the lives of residents who moved in there. Managers were free to choose the group living home environment, equipping, creation of home environment.

Some of the views expressed by the experts in the first phase were assessed doubtfully in the second phase. It was not entirely agreed with the statement that the first group living homes were inhabited by the “strongest” residents, therefore, in the long term, “weaker” inhabitants would join as these homes develop. This doubt suggests that the remaining residents of care institutions are viewed positively and are thought to potentially live in the community, as well. One manager said in an interview that *“I’ve got two group living homes, and I see people getting stronger, becoming more independent, so I want to have more.”* The experts also did not reach the general conclusion that the institutions subordinate to MoSSL are given more favourable conditions (than other participants: municipalities and NGOs) to participate in the transformation process.

When assessing the role of care institutions, it can be stated that the former most active opponents of the transformation have eventually become its implementers. In terms of the chronological system, activity-wise, social care institutions have exchanged places

with NGOs - NGO activeness has diminished over time, while social care institutions have strengthened. The crucial role, authority and prestige of the heads of institutions, which influence the opinion, awareness and preparation for the transformation of other micro-systems - employees, residents and their relatives - are emphasized. It is important to note that the preparation of part of the residents for the transformation depends on the position of the social care institution administration. Even if it is assumed that individuals are given the opportunity to settle in group living homes, the administration first “selects” the potential settlers, and only then is the possibility of moving to group living homes discussed with them.

**People with disabilities are treated as objects of transformation.** People with disabilities are a key group of people driving the institutional care transformation. The preamble to the Convention on the Rights of Persons with Disabilities stipulates that persons with disabilities should have the opportunity to participate actively in decision-making on policies’ directions and programs, including those that are of direct concern to them. However, experts agree that informing people with disabilities about new community services is one of the weakest areas of implementation of the transformation. Lithuanian researchers noticed this back in 2015: *“In the social care system, information on the transformation is available on a hierarchical basis: the administration of an institution knows the most, it is the one to decide what and how to tell the employees of institutions, and they in turn provide information to institutional clients”* (“Psichikos sveikatos perspektyvos“ (Mental Health Perspectives)). The “voice” of people with disabilities, like the transformation itself, should be viewed at from two perspectives, including people with disabilities living in institutions and people with disabilities living in the community. It is important to note that in the first case, the opinion of people with disabilities is greatly influenced by the opinion of the employees working directly with them. Due to the closed institutional care system and the remoteness of the

institutions, the employees are the ones who pass on the basic information to the clients. Experts agree that the involvement of people living in care institutions in the planning and evaluation of processes is understood too narrowly. Residents' councils operate in care institutions, however their decisions, as experts believe, often do not go beyond the institutional boundaries. The only contact of the social care institutions residents with the "outside" world was the assessment of the individual needs of people with disabilities, carried out by independent experts and which allowed the views of people with disabilities to be heard. However, such an expression of participation is limited and subject to criticism, demonstrating a narrow understanding of the right of people with disabilities to participate in decision-making. People with disabilities could only speak out for motivation to move to other community-type services, which can in no way be linked to the real inclusion of people with disabilities and their right to decision-making. The study of the needs of the residents and the results of individual planning were used to collect statistics in order to estimate the need for the developed infrastructure and to assess what type of accommodation services for people with disabilities is needed, e.g. specialized nursing and care, group living, independent living homes or sheltered housing.

**Positive results of transformation.** The opinion of the experts on the positive results of the transformation makes it possible to distinguish the changing public opinion and the development of the diversity of community services. In the first case, society, confronted with transformation actions in one way or another, gradually changes its opinion of people with disabilities, at the same time the macro-system changes. Even if that opinion is not positive, but, on the contrary, hostility is visible, the rudiment of the discourse can be distinguished as a positive result of the transformation: people whose existence was not even known fall into the horizon of the community and all society. Another positive aspect is the variety of new community services for people with disabilities that aim to develop or



maintain the independence of people with disabilities while preventing institutional care. These trends create preconditions for the development of micro-systems in some domestic communities.

**Failures in the transformation process.** It was already mentioned that experts distinguish hostile societal attitudes towards people with disabilities as a major obstacle to achieving the goals of the transformation. In general, barriers to transformation arise as a result of poor process and decision-making, i.e. each action must be maximally determined and coordinated among different participants in the transformation.

Another important statement highlighted by experts is the lack of understanding of cross-sectoral responsibilities. Experts unanimously agreed that social care institutions are a handy condition for abandoning “undesirable” clients, i.e. those in need of health care services eventually become users of social security services, receiving long-term social care covering the organization of health care services. According to Pūras (2019), 20 years ago psychiatric hospitals successfully “cleaned up” and *“people were removed from the patient category and transferred to the category of state-supported wards”, “the health system writes off people as people with psychosocial disabilities and other mental health disorders receive only medication and hospitalizations, but nothing more”*(para. 16). The lack of cross-sectoral responsibility is closely related to the statement made by other experts - the non-existence of cross-sectoral cooperation. All ministries implement specific measures and projects related to the integration of people with disabilities into the community, however the measures are not compatible with each other. If group homes for children with disabilities are set up in a particular area, the education of children, the adaptation of schools, the development of pedagogical competences, the organization of health care services, public education should be organized in that community, but the measures provided are uncoordinated due to the lack of both cross-sectoral responsibilities and to non-cooperation. These transformational

failures exist not only at the level of different ministries but also at the level of other interested groups. According to experts, equal responsibility and cooperation is not a feature of different ministries, municipalities and NGOs. Each country implements its functions. It is believed that too much “knowledge” prevails in the transformation process, which means that each participant in the transformation knows how the transformation is to be implemented, but the opinions of the participants often do not coincide. It is considered that this “expertisness” is not flexible enough. As experts have noted, competition arises both among participants in a particular sector and across different sectors. Strong competition is observed across NGOs. There is a general consensus that a particular NGO is unique in the service it provides or in an area where it feels strong and is reluctant to share its experiences and competencies. In other words, NGOs do not want to let competitors into their field. The study also revealed a lack of cooperation across NGOs. For example, organizations hired to develop new community services often disagreed on how a particular service should be organized, and the NGO sector is treated as being closest to people, i.e. being aware of people’s needs and the means to meet those needs.

Experts identify the non-functioning of the cross-institutional monitoring group as one of the main obstacles to the successful implementation of the transformation. According to the regulations of the cross-institutional monitoring working group, the purpose of the group’s activities is to monitor the implementation of the measures of the transformation action plan and to provide MoSSL management with information, recommendations and suggestions on the results of the monitoring. According to the experts, in practice it is not the monitoring group that coordinates the work of the group, but the MoSSL itself, which leaves the objectives of monitoring unclear. The transformation management group, which decides on the implementation of the transformation directions, makes decisions on what information to present at the meetings of the monitoring group.

This discrepancy is considered to be due to the fact that both the transformation management group and the cross-institutional monitoring group are headed by the same person - the Deputy Minister of MoSSL, the Deputy Head, respectively - a representative of the Ministry. If the monitoring group were led by a non-MoSSL representative, more effective monitoring actions could be implemented. MoSSL could only organize the technical service of the group - to provide meeting places, necessary means, to provide the necessary information at the request of the group members. The current monitoring group is more formal than real - it presents *post factum* decisions and implemented actions, therefore the background of the group's activity is more informative.

The experts also identified the transformation actions related to the provision of experimental services as failures to the transformation process. There is no mechanism to oblige the evaluation of experimental services covering both the principal's and the service provider's feedback - the identification of positive and negative results, which would be provided to the institution responsible for organizing, planning, providing and improving services. Another important logical discrepancy in the transformation process is the organization of training. Experts noted that experimental services provided initially are followed by training. Training topics are "top-down", i.e. an analysis of what training professionals need should be carried out initially, however such analysis is not carried out or is carried out in a fragmented way. E.g., the transformation monitoring group is "asked" what training needs to be organized, and the answers are given without analyzing the need, presented in way "*what is on the tip of the tongue at that time*". Another training issue is related to public procurement rules - in order to be cost-efficient, training is organized by choosing the lowest tender price. The training provider does not need to submit a training program, it is prepared only after winning a procurement contract. Sometimes it turns out that the topic the winner needs is completely new, so training materials need to be

collected fast. At this point, we also observe the lack of practical experience, which leads to relatively poor training results. Experts mentioned that the training did not create conditions for the sustainability of training, e.g. experts involved in the preparation of the descriptions of new community services were able to provide training to various professionals in order to avoid sustainability, efficiency and different interpretations of the service, however the procurement conditions did not provide for this, and a participant holding a managerial position did not “bother” to bypass this discrepancy, e.g. by choosing the criterion of economic efficiency rather than the lowest price.

The experts agree that it was a great mistake that the transformation processes were “built” on the negative attitudes of care institutions and municipal administrations towards the transformation. It is argued that a lot of work had to be done in the beginning to change the role of transformation participants in investing in attitudinal change, mental health literacy. The disunity of the participants in the transformation and the negative attitudes led to the fact that the transformation was implemented on the principle of non-cooperation, which resulted in the risk of transinstitutionalization.

The analysis of transformation failures also highlighted the negative consequences of the transformation process - a new wave of stigmatization in media, confrontational communities and tensions across different transformation participants at all stages of decision-making: planning, alternative selection, implementation, monitoring, control, providing feedback. This confirms both the risks mentioned in the agency theory and shows that transformation “wounds” are found in every part of the ecological system.

**Summary.** The results of the first phase of the research revealed that each participant in the transformation gets involved in the planning and implementation of the transformation process differently. MoSSL coordinates transformation measures at the national level, while municipalities, NGOs and social care institutions

implement the development of community services at the local level. Municipalities make decisions on the implementation of transformation measures related to infrastructure development in their territory. The involvement of social care institutions in the restructuring is crucial for MoSSL, as the institution with the rights and responsibilities of the owner of the institutions. The involvement of NGOs in the transformation is based on project opportunities and they mainly act as providers of experimental services. Therefore, first of all, the different opportunities for the participants of the transformation to participate in the transformation process become apparent. Although the participants implementing the measures do not cooperate with each other, they are interdependent. Dependence is determined by the different rights and obligations of the participants, granted in accordance with the procedure provided by legislation, available material and human resources. The research highlighted two main dimensions of the hierarchical relationship, one between MoSSL and social care institutions, the other between municipalities and NGOs. In the first case, the hierarchy manifests itself in a higher level of decision-making, in the second - the allocation of financial resources.

The overall consensus building of the expert group also revealed other important features of the interaction across the transformation participants that are not regulated (i.e. not formally defined), however operate informally. To put it more simply, this can be described as an informal communication among the participants in the transformation process (certainly, it is important not to forget the informal role of politicians here), which complies with the risks identified in the agency theory. This identification and “scanning” of the risks set by the agency theory through the overall conclusions reached in this research highlights the complex role of MoSSL as a key transformation coordinator. Risks that “occur” in the overall transformation context to MoSSL act as mutually supportive and reinforcing in interactions with other participants. As shown in fig. No

1, there are particularly strong links across some transformation participants based on the pursuit of personal gain (e.g., between the Seimas members and social care institutions, between social care institutions and municipalities), while the accountability of operational efficiency is directed to the MoSSL itself, which is demanded by both politicians and NGOs. Municipalities are autonomous with regard to MoSSL, and the criteria of the operational efficiency of MoSSL is in fact applied only by social care institutions. The study experts identified other important communication directions, the necessity of which is significant in the transformation process, however the connections have been cut, e.g. across NGOs, between social care institutions and NGOs, between municipalities and social care institutions (to the extent relating to the establishment of group living homes).

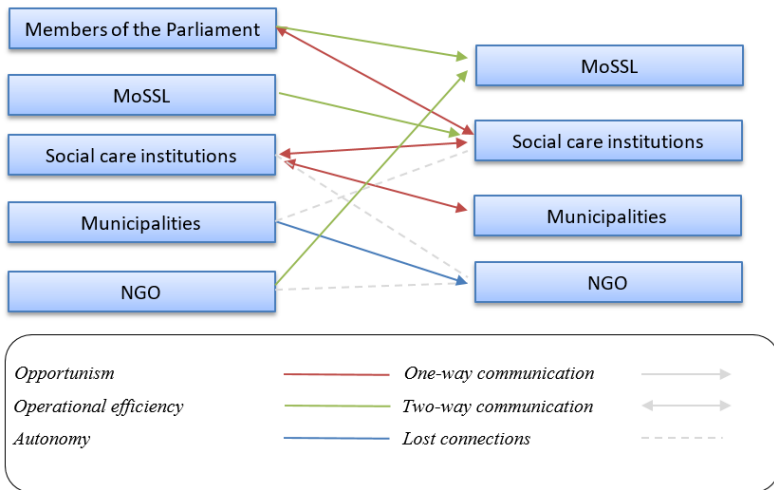


Figure 1. Communication of Transformation Participants from the Perspective of Agency Theory

The transformation is missing a systematic mechanism that involves all participants. When a municipality refuses to build a

community service infrastructure on its territory, it is developed by MoSSL-subordinated social care institutions, which fill in a “gap” in the region. NGOs can participate in the transformation as providers of training, preparation of methodological documents and services, however their involvement is determined by public procurement or project funding rules, as well as the limited nature of projects resulting from the start and end of the project. NGOs could also be involved in the transformation as owners of new infrastructure, but this is a decision for municipalities. Consequently, the coordination of transformation measures at local level is uneven and unbalanced.

All participants in the transformation have opportunistic goals in terms of the transformation. MoSSL seeks to account to the EU for the use of its funds, municipalities - to create the infrastructure in order to eventually accommodate people from their territory, NGOs - to maintain their activities, social care institutions - to continue its activities as an organization. All the motivations revealed are based on the implementation of the organization’s activities, but do not deal with people with disabilities, who are not only not included in the transformation planning process, but also participate in it as objects.

The results of the first research provided directions for the implementation of the other two researches of the dissertation - the analysis of the sustainability of the development of community services and the implementation of transformation in the community. The analysis of the expert opinion revealed the main failures of the transformation process: gaps in the financial mechanism of social services, the problematic nature of the implementation of the transformation, as a project with beginning and end, but not systematic social policy, community resistance, therefore these aspects were researched and examined in subsequent researches.

### 3.2. Institutional care transformation: document analysis

The aim of this research was to gather the information contained in the written documents on the implementation of the transformation, to evaluate it in the context of the set transformation objectives and to compare it with the data obtained in the first research. Document analysis was performed by distinguishing three main sources of information:

- Domestically applied institutionalized mechanisms for monitoring the transformation and / or the Convention. The study examined the formalized goals of the working groups and the actions recorded in the meetings.
- Normative legislation regulating social services policy. This part examines changes in the legal framework.
- Municipal social service plans disclosing the practical side of the implementation of the transformation.

The identified sources of information include the main reference points of the analysis: monitoring mechanisms, changes in the legal system and planning of community services.

**Monitoring of transformation in working groups.** In accordance with the procedure established by legislation, the implementation of the provisions of the Convention is monitored in three formalized working groups: (1) the cross-institutional transformation monitoring group; 2) the Council on Disability Affairs; 3) the Monitoring Commission on the Rights of People with Disabilities. The analysis of the protocols of these working groups enabled to summarize the main conclusions:

- The cross-institutional monitoring group is more formal than real, its activities in practice are based on the provision of information from MoSSL. Discussions on relevant transformation issues are fragmented, there is no systematic approach to a consistent transformation process. In addition, the activities of this working



group are misbalanced by the principle of power due to the participation of MoSSL representatives in the activities of the group, as well as unequal attention to different DeI target groups: children and people with disabilities.

- The work of the Council on Disability Affairs is also rather fragmented in the context of the issues analyzed, i.e. when aiming to cover everything, there is no focus on a consistent problem solving left. There is little DeI context and service development in the activities of this working group. Although the group is dominated by the representatives of associations of people with disabilities, the representation of different target groups results in insufficient attention being paid to people with psychosocial disabilities.

- The activities of the Commission on the Rights of Persons with Disabilities is most responsive to its objective of monitoring the Convention. However, the principals of the transformation do not pay enough attention to the opinion of this group, and the legal framework does not create the necessary preconditions to have a decisive impact on the implemented actions.

**Incompatibility of transformation measures.** The transformation measures are financed by the European Social Fund (ESF) and the European Regional Development Fund (ERDF). The project (No 08.4.1-ESFA-V-405-01-0001) “Creation of conditions in Lithuania for the sustainable transition from institutional care to family and community-based services” is financed by the ESF. Within the framework of this project, 6 activities are financed: (1) preparation of methodological documents, (2) provision of services, (3) research, (4) training, (5) cluster area and (6) promotion. The aim of the research was to analyze, as well as to check the problem raised during the first research - the inconsistency of the preparation of methodological documents, training and provision of services and incompatibility of these measures.

The analysis of the transformation measures showed that 12 methodological tools were developed during the project - descriptions

of new community services. Only half of them, i.e. six services were provided to people with disabilities and their relatives. Two other services - case management and personal assistant - were provided without the preparation of methodological documents. The descriptions of the training topics were of general nature (e.g. "Training for employees working in social care institutions") and did not allow the identification of training of the provision of a specific service, with the exception of personal assistance training. During the Delphi study, the experts stated that the transformation measures were not interconnected: the services were provided first, and the training was organized only afterwards, while the unapproved service descriptions create uncertainty as to how the new services should be provided. It is important to mention that only one methodical document describing the provision of retreat services has been "converted" into legislation that sets common rules and requirements for the provision of such services. In this context, it can be stated that most of the transformation measures related to the development of services remained implemented only within the framework of the project, all but one of the services remained unapproved methodological documents, the content of which was not checked either by legislation drafting specialists or e.g. social work professionals. Therefore, no imperatives or legislation have emerged that would dictate rules for the provision of services to micro-systems for people with disabilities.

#### **Prioritization of people with disabilities at municipal level.**

As the transformation is being implemented in six regions of the country: Vilnius, Kaunas, Šiauliai, Marijampolė, Telšiai and Tauragė, the social service plans of all 36 municipalities located in the mentioned regions have been analyzed. Slightly more than a half (52.8%) of the social service plans were the plans of 2020, the rest was the plans of 2019. It is worth noting that the major part of the social service plans are approved by the decision of municipal councils only

in the first quarter of the current year resulting in a mismatch in the timeliness of the implementation of specific plans.

Summarizing the factual information about people with disabilities living in municipalities, it can be observed that they make up 5.98% of municipal population. Children with disabilities make up 0.54% of municipal population. In 88.9% of municipalities, the biggest determinant of the need for social services is the aging of the population. Disability is not far behind - 86.1%. In the third place - lack of social skills and inability to take proper care of children (77.8%).

The municipal social service plans also indicate the priority target groups on which the social service plan is focused. The most highlighted priority group of service recipients are adults with disabilities, followed by families at social risk and the elderly.

Such prioritization of people with disabilities presupposes the idea that municipalities concentrate a significant part of resources on solving social problems of people with disabilities, and consistent efforts of the municipality to implement transformation measures can be expected. However, only two municipalities can identify a clear and consistent DeI plan, 16% provides a brief, fragmentary description, 30% of municipalities say they participate in the MoSSL program, almost in half of them (47.22%), the topic of DeI is not discussed at all. These data reflect that in municipalities, the topic of DeI is not a part of the priority target group - people with disabilities. The results of the analysis also substantiate and supplement the problems revealed in the first research - municipalities are not inclined to include new community experimental services in the planning, nor are they the initiators of the transformation. On the one hand, this can be explained by the fact that long-term social care services remain dominant - municipalities identify their demand as the greatest (69.4%). By returning to DeI perspective, it is known that long-term social care can be provided not only in large inpatient care facilities but also in group living homes, and social care related to accommodation can be

provided in independent living homes or sheltered housing. However, in more than half of the municipalities (57.1%) persons do not have the opportunity to live in independent living homes. In the municipalities under research, 390 persons live in independent living homes, however this number may be significantly smaller, as independent living homes are also intended for elderly and young people after institutional care. 68.6% of residents of municipalities do not have the opportunity to live in group living homes. Therefore, institutional care in large inpatient care institutions remains dominant. This phenomenon is explained by the results of the first research, which highlight both the shortcomings of social care financing and the “cheap conditions” for municipalities to accommodate people in large social care institutions.

**Minimal changes in relocation of people with disabilities to community.** SWOT analysis was performed to analyze the municipal social service plans. It has been chosen as a tool to help the researcher identify the strengths and weaknesses, anticipate the opportunities and threats associated with the implementation of the transformation, i.e. based on the information provided in the municipal plans, when structuring it, it was aimed to formulate the features of the transformation as an agenturization process that should be highlighted and determined before MoSSL “assigns” a specific task to the transformation participants. The analysis was performed on the principle of the “snowball”, by consistently recording the content of municipal social plan services. The statements were summed up according to repetitions.

The SWOT analysis revealed that the weaknesses identified by municipalities are mainly related to the shortcomings of human capital - underdeveloped network of community services, passive participation of communities in the provision of public services, lack of volunteering, insufficient cross-institutional cooperation. All these aspects suggest that the meso-system level must be activated, in which various micro-systems providing services to people with disabilities

interact. Meanwhile, threats arise at the micro level - the number of service recipients is increasing and there are not enough employees in the field of social services, which means the weakness of micro-systems. On the other hand, the main strengths of the municipality are focused on different levels of the system. It can be assumed that some weaknesses are “filled up” with existing strengths, i.e. the lack of community services can be explained by the increase in the number of service recipients at home.

**Summary.** When researching the transformation processes, various written documents related to the progress of the transformation implementation can be found. Criticism of the implementation of inappropriate measures can be investigated in the institutionalized working groups responsible for monitoring the Convention, the development of services - in the legal acts regulating social services and in the municipal social service plans.

In Lithuania, three main working groups have been institutionalized, which are authorized with the monitoring of the Convention in accordance with the procedure established by law. Although the goals of these working groups are similar to each other, their practice differs. Even though the cross-institutional transformation monitoring group is “closest” to the implementation of transformation measures, it is coordinated by MoSSL, and the meeting issues raised by the transformation participants (mainly NGOs) also reflected the concerns raised by experts in the first research. The activities of the Council on Disability Affairs is broad in scope and more focused on the implementation of other articles of the Convention. The issue of institutional care transformation is not discussed within this working group. The Monitoring Commission on the Rights of People with Disabilities strongly criticizes the segregating services created during the transformation - group living homes and sheltered workshops, however the “voice” of this commission has no effect, i.e. the planned measures continue to be implemented.

The analysis of institutional care measures showed that the three interthematical and interdependent areas - descriptions of community service development, service provision and training - are not interconnected and not interdependent - neither thematically nor chronologically. Many different methodologies have been developed, but only a few services have been tested, general trainings have been carried out without reflecting a specific training topic. Only one training topic (for the provision of a personal assistant service) reflected the content of the service, yet no methodological description was prepared for this service alone. This service was also available to a very small number of recipients compared to other experimental services.

Although various services are being developed during the transformation, the providers of which may also be different, as Žalimienė (2006) confirms, the current financing scheme and practice of social services in Lithuania do not create sufficient conditions for the diversification of the services market.

The analysis of municipal social services and regional transformation investment plans revealed that municipalities are not an active participant in transformation - the implementation of transformation measures is poorly reflected in municipal social service plans; in all cases, community services are not provided in even half of the municipalities involved in the transformation. Inpatient care remains dominant at the municipal level, which shows that neither micro-system nor meso-system are being expanded.

### 3.3. Institutional care transformation: case of Marijampolė municipality

At the level of the exo-system, there are various groups that form a certain common environment. A person with a disability is not an active participant in this environment, but is affected by it through one of the micro-systems (e.g. city government, local politicians,

community, social service institutions, etc.). Therefore, this part of the research analyzes how certain micro-systems, in which a person with a disability is not directly involved, have been involved or involved in the transformation processes and how the activities of these micro-systems affect the group of people with disabilities.

**Community awareness last of all.** Document analysis revealed that communities were the last to learn about the neighbourhood of people with disabilities. Initially, MoSSL informed the municipal administration, which had to select specific locations for the establishment of group living homes. Subsequently, the municipality informed the members of the council, and the decisions made by the municipal council were presented to the local communities. The document analysis showed that the communities became aware of the neighbourhood of people with disabilities a year after MoSSL addressed the municipal administration. Informing the community usually takes place on a designated land plot by banging in a “peg” that announces the planned neighbourhood of people with disabilities. This information complements the results of the first research: effective communication and community awareness do not take place at the level of either the ministry, in this particular case, the corresponding macro-system, or self-governance, the corresponding exo-system. Narrower systems may not have any knowledge without further interest in the transformation, so public relations, communication, and the publicity strategy of the transformation are considered to be one of the weakest links in the process. According to Krause (1992), community members are seen as “obstacles” to be overcome, not as partners in the determination process of the locations. Personal and subjective beliefs are far more powerful than the potential impact of a new institution (Martin, 2000). According to this statement, in the case of transformation, not only the informing of the community, but also systematic change of attitudes is important. Such practice of (non) inclusion of members of the community *de jure*, provokes anger and dissatisfaction *de facto*, which is based not only

on hostility towards people with disabilities in the neighbourhood, but also on non-consultation and non-cooperation with the community.

**We support integration, but only not in our neighbourhood.**

By analyzing the community's speeches in media channels, public meetings, and communication with authorities, there is a positive support for the idea and goals of the community's institutional care transformation. One of the main motives declared is a non-adaptation of the intended environment. As one member of the community said on the radio show: *"How happy would they be to live in a messy neighbourhood when we have such a wonderful city?"* Another member of the community said: *"Our neighbourhood is not suitable - you need to look for another one."* A member of the council mentioned at one council meeting that *"it is a tick living zone"*. In this case, the community seems to be trying to instill the idea that other places for people with disabilities would be more suitable, better, however, this situation is not about the improvement of the infrastructure of the community where group living homes are planned to be built, which would correlate with the construction of group living homes. The term NIMBY ("not in my back yard") is used to express the residents' resistance to the proposed changes in their community. This association usually occurs when addressing environmental issues, questions of residential prestige, or the integration of socially vulnerable groups. People with psychosocial disabilities are among the social groups most affected by NIMBY exclusion. It is believed that NIMBY not only defends the interests of its community, but also makes minority communities victims, as they are not only not accepted into the community, but other, more remote conditions are sought for them (Gerrard, 1994).

The first resonant case, when the community uprose against the construction of group living homes, occurred in the summer of 2019, in Žiežmariai, and "rolled" across the entire Lithuania, including Biržai, Kretinga, Rokiškis, Šakiai, Marijampolė, Skaudvilė, etc. At the time, there were plenty of articles in the media dominated by



discrimination and fear of people with mental or intellectual disabilities.

**Transformation is a resource for political advertising.** The first phase of the research revealed the lack of political leadership or the face of a particular politician to implement the transformation. At this stage of the research, the phenomenon of political leadership emerged, when the context of the transformation in the pre-election period was exploited by politicians to carry out campaign advertising. Transformation is usually presented in a negative context. It is not the goals of the transformation that are criticized, but the process of its implementation, which is usually directed at the municipal administration or municipal leaders. The municipal administration is often described as: *“not consulting”, “not coordinating”, “disregarding the interests of the residents”, “seeking to launder money, push through the project”*. In addition to municipal leaders, other political parties have been criticized as well. It should be noted that a significant number of council members were candidates for members of the Seimas. The content reflected on the personal social network accounts of municipal councils or members of the Seimas was analogous in meetings with communities. One council member spoke at a meeting with the community that community members should be compensated for the harm they suffer as a result of the neighbourhood of people with disabilities. Such political slogans plaited the speeches of most politicians in various public spaces when questioning the ongoing transformation. The transformation was used as a resource of political advertising not only by the members of the municipal council, but also by a member of the Seimas, who repeatedly stated that *“group living homes cannot be created in the municipality until all members of the community agree to it”*.

Linking this phenomenon of politicisation to the results of the first research, it can be concluded that the phenomenon of political leadership on the topic of transformation is quite diverse. First of all, the consistent implementation of the transformation at the national

level lacks political leadership in terms of both the government, the parties, in the sense of a particular personality, so the unattractive topic of the transformation is being implemented within the framework of MoSSL as an institution. Second, the transformation of institutional care, which is perceived as the breakdown of large institutions into smaller ones, is unfavourable to some politicians as it is easier to get a larger number of votes in a large institution for people with disabilities. Third, community resistance to the construction of group living homes is also being exploited as a resource for political advertising and the desire to attract as many voters as possible. Therefore, the context of the transformation is exploited for opportunistic purposes, judging through the prism of handiness of engaging in its processes, but it is not a summoning topic that would be part of a systematic social policy.

**Positive aspects of the development of community-identified community services.** Outside any real motives and ambiguities of the community members, it can be said that the community members identify the conditions that are necessary for the full life of people with disabilities in the community. Basically, it is the adaptation of a safe living environment to everyday life - paved sidewalks, street lighting, crossings, bus stops, further on, establishment of leisure areas: parks, recreation zones, day care services. In the discourse of community members, one can see extremely important accents that coincide with the arguments of critics of the DeI system. First of all, the massive number of people in one home is criticized. According to community members, *“a 6-acre plot is unsuitable for ten people to live in one house.”* Another important argumentation was based on the unsuitability of the neighbourhood: *“How will those people with disabilities reach Marijampolė, which is 4 kilometres away? A person will not be able to go to the library or the store. What kind of integration can we talk about? How will you ensure their employment?”* The discourse of community members manoeuvring between fears and securing the rights of people with disabilities

reveals that community members, unwilling to voice out stigmatizing attitudes toward people with disabilities, seek resources for transformation problems ignored at other levels of the micro-system. For example, in Skaudvilė, the community opposed to the construction of group living homes quoted articles by prof. J. Ruškus, in which he criticizes the creation of new institutions and the continuing segregation of people with disabilities. Communities are beginning to gather evidence-based research, experiences from other countries that some participants in transformation (MoSSL, municipalities, and social care institutions) fear to speak out about. In this process, communities also contribute to the transformation process and, in the absence of systematic, clear and consistent communication, exploit the problematic context of transformation opportunistically and become a kind of participant in transformation that cannot be forgotten or ignored.

**Manipulations on behalf of MoSSL.** During the council meetings, the position of MoSSL was regularly mentioned, which was often pictured ambiguously, i.e. different views of MoSSL were expressed. For the members of the municipal council who supported the transformation actions, the position of MoSSL was supportive, for those who were against the transformation actions in Marijampolė - the position of MoSSL was approving, i.e., on the one hand, it was said that *“the ministry praises us, calls it a role model municipality in the field of publicity”*, on the other hand, *“the ministry agrees that the transformation, as it is “pushed through in Marijampolė, cannot take place”*”. There is ambiguity in saying that *“a liar Deputy Minister tells you one thing and tells us another”*. It is important to note that there have been opinions that underestimate MoSSL itself, saying that *“the ministry’s approach is below a skirting board”*, aiming to say that the ministry moralizes in meetings with communities about the reluctance of most municipal members to accept people with disabilities to their communities.

The report on the official website of the Seimas on the visit of the Member of the Seimas J. Džiugelis to Marijampolė reads: “*the dismissive ministry’s view of this reform and the arrogant position of self-government have led to a situation where we have not only a played-off community, but also a rather seriously stuck important project*”. Therefore, it is clear again at this point that there is also a lack of consensus among the highest authorities and they demonstrate public discontent in the public sphere. Basically, these failures occur in the meso-system when we see that different micro-systems (MoSSL, municipality and community) do not communicate with each other, while the ministry, as the key principal of the transformation, becomes responsible for the implementation of all transformation measures.

**Avoiding confrontation with people with disabilities.** During the observation, the author visited two already functioning group living homes, which were established in Marijampolė in August 2018 and February 2019. During the council meetings and meetings with communities, the current experience of group life homes was used as a counter-argument to various community fears: it was suggested to make visits to existing homes, meet people living there, talk to neighbours, however, neither contradictory council members nor opposing communities visited the already established group living homes.

During one meeting with the community members organized by the municipality, a resident of the group living home took the stage and read a speech written by her. The main idea of the text revolved around the request of people with disabilities to the community to let the latter ones into their lives. The speech was ended with the words: “*We hear you are afraid of us, but we are afraid of you even more.*” At this point, it is important to recall the moment when we talked about the fear of hostility in the community of people with disabilities, which can lead them not only to isolation, but also to distancing themselves in order to avoid hostility and stress. Members of the community

present at the meeting at the time demonstrated a derogatory attitude, shouting that “*somebody wrote that speech for her*” or “*they chose one normal out of a hundred.*” The opinion of the community members is strongly influenced by the medical model of disability, which is so entrenched that it is not only sought to segregate people with disabilities, but also confrontation with them is avoided. Such behaviour seems to indicate that the dominant approach is acceptable and that no steps are being taken to change it. Meanwhile, the changes taking place in the micro-systems of community members are ignored.

**Summary.** According to Pūras ir Šumskienė (2012), persons living in institutions “*are individuals who do not have a significant role in society and are considered prospectless*”, who are “*interesting only to the employees servicing them, relatives of the clients and public authorities administering social care institutions*” (p. 88). However, such an assessment is no longer relevant in today’s context, where people with disabilities are seen as potential neighbours, community residents and recipients of public services following the start of the transformation. The process of the transformation of care homes has provoked a wider confrontation of social groups with people with disabilities.

The implementation of the transformation at the political and local levels is a different process. At the local level, different transformation participants emerge playing a crucial role in the implementation of transformation processes. These are different micro-systems that play an active role at different levels of the system: the unification of community members’ micro-systems is particularly relevant at the macro level, as well as at the exo level, where they become participants in the negotiation process with local government and local politicians. The attitude of the community influences the chances of people with disabilities to become full members of the community. Local politicians engage in the process lead by selfish goals that are related to increasing of personal popularity in the pre-election period.

As a participant in the transformation, NGOs did not participate in this process, nor did they participate in the advocacy processes for the rights of people with disabilities. Although NGOs in Marijampolė provide various services tested during the transformation, in this situation they were passive observers. The process also involved the existing micro-systems of people with disabilities, the inhabitants of group life homes, however they seemed to be pushed out of the field of discourse and underestimated. This confirms the statements of ecological systems theory about the power of a macro-system with respect to micro-systems. The analysis of the community case substantiates the statement that the transformation of institutional care is extremely complicated and complex, its course depends not only on the interaction of transformation participants, but also on other important, but currently ignored problems - processes within local communities.

## CONCLUSIONS

1. The combination of agencies and ecological systems theories is a new way to study the deinstitutionalisation of care for people with disabilities. Complementing each other, these theories allowed for a comprehensive analysis of the phenomenon under study and the identification of the main obstacles to the transformation of institutional care and the development of community services. The combination of theories provided a framework for empirical analysis, which revealed essential, and at the same time very precise barriers to transformation, the assessment of which in Lithuania before this study was fragmentary, covering only a part of the research phenomenon.

2. The process of transformation in Lithuania is identical to the failures experienced by other post-socialist countries in trying to reform the social care system, as the same mistakes are repeated. Most of the funding goes to highly criticized group living homes, which are seen by human rights activists as mini-institutions, with a similar

“institutional culture” in care institutions that is close to a medical assessment of the disability model that emphasizes isolation and segregation. Meanwhile, personal assistance is minimally developed and operate only within the framework of projects with start and end.

3. The transformation of institutional care is not a purposeful part of the state social policy. The implementation of the transformation is related to the financing of the EU structural funds, on which the scopes of financing of the transformation measures depends. The transformation is implemented on the basis of an incremental decision-making model, where only goals that can be achieved in the current conditions and available resources are set, and the political process develops through trials and failures. Decisions are made without any overall plan, systematic analysis, control or coordination. Alternatives to institutional care that do not involve accommodation are funded within the framework of projects, so there is a risk of “projectivity” related to non-continuity of services and harm to an individual when the service ends after the project is over and some people can return to a social care institution.

4. The transformation of institutional care is perceived and implemented only within the framework of the social security system, therefore the concepts of deinstitutionalisation and community services are not harmonized, the latter correspond to only a small part of the UN Convention on the Rights of Persons with Disabilities. By attributing the DeI process only to the social security sector, there remains a high risk of transinstitutionalization, as it lacks the resources and competencies to ensure a full life for people with disabilities in the community. Community services are perceived as social services that do not cover all other sectors: health, education, employment, culture, politics, etc., so the change in the macro-system is very minor and occupies a small part of the system.

5. The transformation process is neither coordinated in terms of delegation nor performance. The implementation of transformation measures is left to “laissez-fair” scenario, which depends not only on

the characteristics of the participants in the transformation, but also on the problems unresolved at the beginning of the transformation: uncertainty of inter-organizational interaction, information asymmetry, absence of accountability and integrity control mechanism and ineffective monitoring.

6. The motives of the participants in the transformation (municipalities, non-governmental organizations and social care institutions) are influenced by opportunistic goals and in one's interest, therefore they are involved in the transformation process in a fragmented manner and only when it is beneficial. When declaring the implementation of the transformation, the municipalities use the autonomy of the municipality regarding the implementation of the restructuring measures. NGOs depend on local government, opportunities of project activities and are unequal participants in the process, while social care institutions fill in the "gaps" arising from the inaction of municipalities and NGOs - they become providers of social services and in a sense "leaders" of transformation. The participants in the transformation process perform different tasks and roles assigned to them in the transformation process, but they do not form a joint team with a "spirit" contributing to the common goal - full life of people with disabilities in the community.

7. Strong competition and non-cooperation prevail among the participants in the transformation. Although competition is viewed positively in the agenturization process, i.e. it is considered that different providers compete with each other to improve the quality and attractiveness of the services provided, but the topic of disability is unattractive due to the prevailing model of medical evaluation and competition is used to exclude people with disabilities, i.e. competing for transfer of responsibility. They have different information at their disposal, the sharing of which depends on the motivation of the individual participant. Opposition and dissatisfaction with each other prevail among the participants of the transformation, therefore the transformation is not implemented in a complex way, i.e. everyone



operates at the level of their own system, is the core of the system, in which people with disabilities seem to disappear and play a secondary role in pursuing selfish goals.

8. People with disabilities participate in the transformation process as objects - recipients of new community services. There is no mechanism for involving people with disabilities in the policy planning, decision-making, monitoring and control process. The exclusion of people with disabilities from the transformation process means that the transformation process itself is affected by the medical model of the disability model, as people with disabilities do not participate in it, and their lives are decided by other participants in the transformation, deciding how much and what services this group of people needs.

9. The transformation does not pay attention to informing and preparing communities about the essence of transformation needs, therefore communities become “obstacles” to the implementation of transformation, resisting the planned changes, as well as, in the long run, significantly affecting the exclusion of new residents. The ultimate goal of the transformation depends on the readiness of the communities, so ignoring their existence as participants in the transformation threatens the implementation of the transformation at all levels of the system.

10. As the whole ecological system experiences “chaos” in the context of transformation - imbalance of system levels, polarization of micro-systems, failure of coherence, stagnation - this determines that the micro-systems of a person or people with disabilities remain unchanged in the long run. The interdependence of different subsystems reveals that in higher systems, especially exo and macro, unresolved issues and actions cannot improve the situation of people with disabilities. The absorption of this micro-system intervention is determined both by its exclusion from the levels of other systems and by social work professionals who are dependent on the position of the administration in social care institutions.

11. The application of agency and ecological system theories has made it possible to identify the main characteristics of transformation participants and transformation problems. The use of these theories and the results of the paper research revealed that the successful implementation of the transformation requires the use and involvement of other participants in the transformation - people with disabilities and their relatives and local communities. An important approach is that the transformation of institutional care must be assessed and planned systematically: by assessing the participants in each system, the problems that arise in their interaction, and the tools to solve these problems. In the absence of a comprehensive plan for solving problems, deinstitutionalisation in the country only remains a transformation of some specific social care institutions, and not a significant change in social services policy.

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Rasa Genienė graduated from Vilnius University in 2013 where she acquired Bachelor's degree in Social Work. In 2015, the author acquired Master's degree in Social Work. During her studies, the author got employed in the Lithuanian community of people with mental disabilities "Giedra" [Eng. Sunshine]. When working in the NGO, the author received EEA Grants funding for the project *Dissemination of the independent living home model and ensuring the protection of human rights in psychiatric hospitals*. This organization was the first that established an independent living home in Lithuania.

In 2016, the author began her doctoral studies of sociology at Vilnius University. At the end of 2018, she started working in the Ministry of Social Security and Labour at Social Services Unit, where she was able to get acquainted with the deinstitutionalisation of care for people with disabilities. In 2020, she was employed as a junior researcher for the project *People and places: transforming community welfare in the process of deinstitutionalisation of care services*. The aim of the project is to analyse how understanding of community welfare and practices of its development are being transformed in the process of deinstitutionalization.

The author takes active interest in various domains of welfare and wellbeing of people with disabilities, such as life in residential care facilities, aspects of family relationships (grand-parenting, motherhood experiences), life satisfaction, leisure in older age. She had published several articles and was a speaker on national and international conferences on various aspects of deinstitutionalization of residential care facilities and development of community-based services.



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