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Analysis of deinstitutionalization of care of people with disabilities in Lithuania

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February 2023

Content

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ABBREVIATIONS

DI – deinstitutionalization

PWD – people with disabilities

ERDF – European regional development fund

ESF – European social fund

MoSSL – Ministry of social security and labour of Lithuania

NGO – non-governmental organizations

Convention – United Nations convention on the rights of people with disabilities

DDA - Department of Disability Affairs under Ministry of social security and labour of Lithuania

GLH – group living homes

SCI – social care institutions

CONCEPTUALIZATION OF DI

On 16 November 2012, Lithuania approved the „Strategic guidelines for deinstitutionalization of social care homes for disabled children, children left without parental care and disabled adults“[1].

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”[2] (Transformation action plan).

These two legal acts are the main documents that guided the implementation of DI. They define the term DI as a transition from institutional care to family and community-based services. However, most of the focus in the last decade has been on the development of GLH, so de facto, for a very long time, DI has been understood as the transformation of large residential care facilities into smaller segments in the community. In Lithuania, the term „DI” is used synonymously with the term „transformation of institutional care”, therefore, this emphasis on the transformation of social care presupposes the reduction and fragmentation of the care system.

Policymakers have established rules that newly established GLH should be prioritized for the relocation of residents of SCI into the community. However, PWD living in the community, who are often dependent on the care of their relatives, were not a priority group, so the prevention of institutional care was rather difficult. In a broad sense, DI 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 DI can turn into trans-institutionalization, which means relocating PWD to a different residential infrastructure, without other components of community services: personal health care, employment, education, political, cultural and other services necessary for a person.

Thus, DI perceptions did not include a prevention component. DI was only aimed at addressing the consequences but not the causes of the problems, i.e. no questions were raised - what to do so that PWD never enter institutions. For many years DI was understood as the **transfer** of people to live in the community, under similar conditions as all members of the community, but there was no thought about the need to address the reasons that determine the admission of individuals to institutions - e.g.

[1] https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.437781?jfwid=q8i88l7l1

[2] https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/e4169490984411e3aad2c022318814db/asr

burden on families, lack of personal support and housing in the community, lack of self-reliance skills and so on.

In practice, at all levels (ministries, municipalities, NGO), DI is understood too narrow – its only about institutions. There is a lack of a complex approach, that institutions are a consequence and to really implement reform, it is necessary to eliminate the causes of problems, which do not lie in the institutions at all.

DATA ABOUT PEOPLE WITH DISABILITIES LIVING IN INSTITUTIONS

b) If these data are available in the country, a description of how many people live in institutional services, in what conditions, what adverse situation in particular and how it is addressed, the structure of support provision for people - the support network (not only social services, also informal support - relatives, community...).

According to the data of the DDA, at the beginning of 2023, 5515 people lived in 33 SCI intended for people with intellectual and/or mental disabilities. 185 people were waiting in line to live in those social care institutions[3]. By comparison, in 2011, there were 6061 people living in residential care facilities, so the number of people in institutional care decreased by only about 9 percent over the decade. On average, about 167 people live in one facility. More than 300 people with disabilities live in the largest social care institutions.

In Lithuania, SCI have historically been established far from cities and towns - mostly in former estates. The history of many institutions goes back a century. Although the living conditions were improved year by year, the main features of the institutional culture remained. Based on 2007-2013 statistics on the use of European Union support, according to Cohesion promotion action programs for the environment and sustainable development priority, renovation of public buildings at the national level measure, many of the country's social care instiurions were renovated. After summarizing the goals of the implemented projects, everyone's aspiration was equal - to ensure economical and efficient energy consumption, to improve working and living conditions.

Investing in the existing social care system created the conditions for the next one for the flourishing of institutionalism “despite the well-known fact that institutional care in large institutions establishes

[3] https://www.ndt.lt/laisvos-vietos-socialines-globos-istaigose/

the prerequisites for systemic human rights violations and is the worst investment in the development of society"[4].

SOCIAL SUPPORT SYSTEM

c) Who is involved in providing support to people and their responsibilities - the system, management and funding of support to people.

The Ministry of social security and labour

According to Article 11 of the Law on Social Services, MoSSL is responsible for the social services policy of the state. MoSSL submits proposals to the Government regarding the development directions of the state social service system and social work and prepares draft legislation related to the allocation, provision of social services, quality standards, etc., in other words, it performs the functions of regulating legislation. Pursuant to Article 16, Part 2, Clause 2 of the Law on Social Integration of the Disabled, MoSSL is responsible for the formulation, organization, coordination and control of the social integration policy for people with disabilities. Also, MoSSL, based on the Law on the Development of Non-Governmental Organizations, is responsible for the formulation of the NGO development policy, its implementation and control, as well as the assessment of the state. Article 19 of the Law on Social Services states that the Government or its authorized institution, in this case MoSSL, establishes, restructures, reorganizes or liquidates social care institutions providing long-term or short-term social care, which are not needed in the territory of every municipality, therefore MoSSL is also indirectly responsible for deinstitutionalization of more than five and a half thousand people living in SCI.

Municipalities

Pursuant to Article 13 of the Law on Social Services, the municipality is responsible for providing social services to residents of its territory by planning and organizing social services, controlling the quality of general social services and social care. The function of the municipality is also to assess and analyze the needs of its residents, based on them to determine the extent and types of provision of social services, to assess and determine the need for financing social services. Pursuant to Article 16, Part 6 of the Law on the Social Integration of the Disabled, municipalities carry out activities in the areas of social integration of the disabled, meeting the special needs of the disabled by assessing

[4] Pūras, D., Šumskienė, E. (2012). Psichikos negalią turinčių asmenų globa Lietuvoje: priklausomybė nuo paveldėtos paslaugų teikimo kultūros. Socialinė teorija, empirija, politika ir praktika. 6, 87–96. https://doi.org/10.15388/STEPP.2012.0.1856

a person's independence in daily activities and providing general and special social services, creating conditions for the PWD to integrate into the community and cooperation with associations of the disabled, and are planned by the municipality in strategic planning documents. In the context of the Convention, municipalities do not have a mandatory function to ensure the implementation of the provisions of the Convention for local residents. The Government only recommends that the Association of Lithuanian Municipalities implement the provisions of the Convention in accordance with its competence. From the NGO side, the municipal council, taking into account the established international priorities and assessing the needs of the local community, determines the long-term development goals of the NGO in the planning documents, the areas of NGO activity to be financed by the municipal budget. The problem of responsibility for the provision of social services arises from the autonomy of the municipality. Pursuant to Article 6, Part 12 of the Law on Local Self-Government, the autonomous function of the municipality is the planning and provision of social services, the establishment and maintenance of social service institutions and cooperation with non-governmental organizations. The municipality's responsibility is to create conditions for the social integration of PWD living in the municipality's territory into the community. The autonomous function means that when implementing it, municipalities have the freedom to initiate decisions, adopt and implement them as determined by the Constitution and laws, and are responsible for the performance of independent functions. In this place, ideological inconsistencies in relation to PWD can be seen - on the one hand, municipalities are responsible for the provision of social services to their residents, on the other hand, municipalities are sufficiently autonomous to decide whether to participate in DI, whether to provide trial (yet unregulated) services, or whether to "let" non-municipal people into their territory with disabilities and many other issues that depend on the role of the municipality in the DI process.

Lithuanian social services system is divided into 3 main service groups: 1) preventive social services, 2) common social services and 3) special social services. The third group is the one in which services are provided when a person's need for certain services is identified.

Special social services	
Social supervision	**Social care**
Support at home	Day social care
Developing, maintaining and/or restoring social skills	Short-term social care

Accommodation in an independent living home	Long-term social care
Social rehabilitation for the disabled in the community	Temporary respite (as care)
Psychosocial support	
Accommodation in sheltered housing	
Temporary respite (as supervision)	

Financing of social services

Based on the provisions of the Social Services Act, social services are financed from the state, municipal budgets, social service institutions, European Union structural funds, foreign funds, support (donations), individual (family) payment for social services and other funds.

General social services and social supervison services for adults with disabilities, children are financed from the municipal budget.

Social care services for families, children's day social care, social rehabilitation for the PWD in the community are financed from municipal budget funds and from state budget grants to municipal budgets.

Social care services for adults with disabilities, children with disabilities (except for persons with severe disabilities) are financed from the municipal budget.

Social care services for persons with severe disabilities are financed from the state budget through special targeted grants to municipal budgets.

Individual payment for social services

The amount of payment for social supervision per person must not exceed 20 percent of the person's income. The amount of payment for long-term social care for an adult must not exceed 80 percent of the person's income, if the value of the person's property is lower than the property value norm established in the municipality of his place of residence. In cases where a person receives targeted compensation for nursing or care (assistance) costs under the Targeted Compensation Act, 100 percent of this compensation is allocated to cover the payment for long-term social care.

It is important to emphasize that according to the Catalog of social services, social care services include a set of various services - from the satisfaction of the basic needs of a person to the

development of daily and working skills. So all these services are included in the price of the service and must be organize in the SCI or GLH, which means that a person living in a SCI or GLH cannot use other community services for which they have to pay. There is a big gap in this area, because people living in SCI do not have the right to attend community day or other centers. Also, in GLH, as a communal form, there are no opportunities to organize targeted employment of individuals. Therefore, legislation must be reviewed in the country in order to ensure flexibility and the choice of individuals to participate in various community activities.

The amount of a person's payment for personal assistance cannot exceed 20 percent of the cost of providing personal assistance and cannot be more than 20 percent of the person's income. Personal assistance is provided free of charge to a person whose income is less than 2 times the amount of state-supported income (157 eur - state-supported income (1)).

The need for social services and personal assistance is determined by social workers appointed according to the procedure established by the municipality. PWD or their relatives must apply to the municipality of their place of residence for the necessary services. Such a system is rather difficult to understand and at the same time difficult to access for people with mental and/or intellectual disabilities, because they lack information, lack of knowledge about their rights, about opportunities - individuals have to seek help themselves, but help itself does not come to the person. There is a lack of proactive approach and timely problem solving. Persons with disabilities are often cared for by relatives who cannot participate in the labor market, at the same time they experience constant overwork, burnout and exhaustion, and those who are no longer able to take care of themselves initiate the placement of a person in an institution. There is a lack of the view that informal care of relatives is not suitable either for the individuals themselves (e.g. due to hyper-care) or for relatives whose rights to an independent life are limited.

THE ROLE OF DIFFERENT ACTORS OF DI PROCESS

DI process is a complex phenomenon taking the involvement of many different sectors and organizations. Each sector or organization has its own functions, responsibilities and competences. This chapter is based on research data conducted in R. Genienė's dissertation, "Development and provision of social services to persons with psychosocial disabilities in the perspective of social care reform", which examines the activities of different actors in DI process - contribution to the DI system, responsibilities, approach, work done, competencies and mutual cooperation. In this chapter, the group of DI participants includes the MoSSL, municipalities, non-governmental organizations,

SCI, PWD and local communities. When implementing DI, the importance of each actor's contribution cannot be ignored, because in the long term, each actor can become an obstacle to the implementation of DI process (Genienė, Šumskienė, Gevorgianienė & Diržienė, 2021[5])

Representation of DI topic in political level

One of the most highlighted obstacles of DI is the lack of political leadership. Although the MoSSL formulates the DI policy, its implementation is largely based on the fulfillment of international obligations rather than political initiatives. For example, since 2012 after the change of four political terms of office, the subject of DI is taken up as a continuous process, and not as a fixed goal of the term to be implemented. Thus, in the context of DI, there is no leader, the face of DI in the country, in contrast to e.g. the political slogan of the former president of the country D. Grybauskaitė - "Lithuania 2020 - without children care homes". Therefore, it is important to emphasize that although the DI of children left without parental care and the care of PWD started at the same time, the DI of children happened faster and more successfully. The President herself chose leadership in the topic of children, so the value support of the topic was constantly heard.

It is important to note that individual politicians, members of the Seimas (Lithuanian Parliament) or members of municipalities exploit the topic of ID, especially when it comes to housing PWD in the neighborhood. It is not uncommon for these persons to raise their ratings and "pick up votes" when communities oppose the neighborhood of PWD. In these situations, the persons who should educate the communities about the implementation of the Convention do the opposite - they speculate, support conflicts, represent the interests of the communities, and support the segregation and discrimination of PWD.

Independence and autonomy of self-government

Based on the competence of municipalities regulated in the Law on Social Services, the municipality is responsible for ensuring the provision of social services to the residents of its territory by planning and organizing social services, controlling the quality of general social services and social care. The

[5] Genienė R., Šumskienė E., Gevorgianienė V., & Mataitytė-Diržienė J. (2021). The Deinstitutionalization of Persons with Psychosocial Disabilities from the Perspective of Ecological Systems Theory. Socialinė Teorija, Empirija, Politika Ir Praktika, 22, 28-43. https://doi.org/10.15388/STEPP.2021.27

municipality assesses and analyzes the needs of social services. However, a complete paradox can be seen in the context of DI - municipalities are not inclined to include new community services in the planning of social services, which are both pilot and newly regulated in the context of DI, and whose purpose is to improve the quality of life of PWD, increase their independence and seek to ensure human rights. For example, although temporary respite and sheltered housing services are regulated in the social services system, no breakthrough is visible at the community level, in terms of service development - there are only several NGO projects or several requests for the organization of the aforementioned services, but no changes are visible at the national level - strong referrals to institutions still dominate culture.

Article 6 of the Law on Local Self-Government, which defines the autonomous functions of municipalities, states that the autonomous function of the municipality is the planning and provision of social services, the establishment, maintenance and cooperation of social service institutions with non-governmental organizations, and the creation of conditions for the social integration of PWD living in the municipality's territory into the community. The autonomous function means that when implementing it, municipalities have the freedom to initiate decisions, adopt and implement them as determined by the Constitution and laws, and are responsible for the performance of independent functions. Self-regulation of municipalities creates the conditions to ignore international legal acts and strategic directions. As shown by studies conducted in Lithuania, municipalities do not make decisions regarding the development of alternative community services. Funding for services for the new year is taken over from year to year using the need of the previous year. Municipalities rarely communicate and cooperate with the non-governmental sector. There are cases when local NGOs feel "defeated" and are "afraid to speak out loud", thinking that they will not receive funding for project activities.

The independence of municipalities in the field of DI is also shown by the cases where some municipalities, using the funds of the 2014-2020 financial period, refused to get involved in the development process of community services, instead of their initiative and in their territory, institutions subordinate to the ministry began to develop services. It also shows the very visible attitude that DI is "Ministry business" and the people living in the institutions are "Ministry people". The research conducted in Lithuania revealed that there is no mechanism that would oblige municipalities to get involved in the development of community services. Such a fact not only substantiates the power instruments available to the municipality for both the Ministry and DI, but also reveals the systematic shortcomings of the transformation itself, since the provision or transfer of instruments to institutions subordinate to the MoSSL continues to support care institutions - at least

as a legal entity, and at most as the same institutional the existence of the culture that is being tried to be abandoned during the DI. The country's experts believe that, unlike the situation now, the initiators of the transformation should be the municipalities, interested in preventing their residents from ending up in stationary care institutions. However, the existing legal system does not oblige municipalities to take care of the quality of care services, nor to be responsible for their residents who have moved to care homes located in another municipality. Paradoxically, institutions subordinate to the MoSSL establish the infrastructure of community services by making efforts to return the residents of municipalities to their community. This is closely related to another statement consolidated by experts that, from the point of view of municipalities, people in institutional care belong to the state, forgetting that they came from a specific municipality, city or town community.

NGOs: from active AI initiators to passive followers

Two main types of NGOs are distinguished according to their operational objectives (Banks and Hulme, 2012, p. 24): supply-side (service-providing organizations) and demand-side (lobbying and seeking to influence public policy). NGOs representing the rights of PWD were the initiators of the DI topic at the beginning of the last decade, but in the long run their role and initiative decreased. A study conducted in Lithuania revealed that NGOs seek the greatest possible organizational benefits in the context of DI. This can be explained by the different motives of NGOs to participate in the DI process - one of them is the opportunity to solve the family situation, the second is the desire to strengthen their political influence, the third is the opportunity to earn extra money from projects for DI or different combinations of these motives. Thus, when assessing the overall systematicity of NGOs in the DI process, their interests often do not coincide with the long-term goals of AI.

Service-providing NGOs participate in project activities aimed at the provision of established services. In this way, the financial incentive allows them to develop alternative services to institutional care, while contributing to the sustainability of NGOs. On the other hand, service-providing NGOs were not involved in the formulation of DI policies, and therefore did not respond to the needs of local communities. This is explained by the original plan itself, when all DI resources were allocated to the transfer of people living in institutions back to the communities, but little attention was paid to prevention, which is necessary to prevent access to SCI. The role of NGOs (service providers) is also missing in projects that are ending - they do not take the initiative to negotiate with municipalities regarding the continuity of the necessary services, on the other hand, this is explained by the already mentioned fact that NGOs feel defeated in municipalities. It is also important to note that there is strong competition between NGOs providing services - each has its

own clientele and is not inclined to allow persons returning from institutions to communities into their activities.

Social care institutions: from resistance to center of power

SCI have been the most active opponents of the DI process since the beginning, because they perceive DI as the breaking up of large care institutions into smaller fragments in the community. However, year by year, SCI have taken a decisive role in the DI process - they were the first in the country that in 2017 founded GLH and "dictated" the practice of establishing these houses, which is still used today. It is true that SCI, having seen that the quality of life of individuals really improves in a smaller environment, gradually began to be less opposed to the establishment of GLH. However, several studies conducted on this topic in the country, which analyze the life of PWD in GLH, revealed that there are still many manifestations of institutional culture in them: strict order and time regime, individuals participate in community activities in groups, not individually, and their agenda is largely decided by the staff. However, it is worth noting that little by little, a breakthrough is visible in some GLH, some individuals move to live in sheltered housing, find employment in the open labor market, use community public services individually or with the help of employees, and engage in activities intended for the wider community, not just for communities for PWD.

SPECIFIC EXPERIENCE AND PRACTICE OF DI PROCESS

d) Specific experience and practice in the country with the change process, DI:

- What has been done and with what outcomes

The largest part of DI is financed by EU Structural Funds investments. Two main directions of investment can be distinguished - development of 1) infrastructure and 2) services. Infrastructure development ("hard investments") is financed by the European Regional Development Fund (ERDF). The development of services ("soft investments"), mainly related to investments in human resources, is financed by the European Social Fund (ESF). It is important to note that state investment funds were also invested in the development of GLH.

Results of infrastructure investments

By using the 2014-2020 ERDF funds were planned to establish 115 infrastructure facilities: 6 (40 places) specialized social care and nursing homes, 68 GLH, 3 independent living homes, 8 sheltered dwellings, 2 day centers, 14 day centers/social workshops and 14 social workshops. However, taking

into account the significantly increased construction prices, it is tentatively planned that at most it will be possible to establish about 49 infrastructure objects: 3 (40 places) specialized social care and nursing homes, 20 GLH, 6 sheltered dwellings, 8 day centers/social workshops and 12 social workshops.

During 2017 - 2022, 41 GLH were established in Lithuania, where 267 adults and 48 children settled, using state budget funds.

Year	Number of GLH	Clients		Municipalities
		Children	Adults	
2017	11	10	61	Kelmė, Telšiai, Kėdainiai, Švenčionys, Akmenė, Kaunas city
2018	14	26	91	Kėdainiai, Visaginas, Kelmė, Panevėžys, Šilutė, Marijampolė, Akmenė, Tauragė, Vilkaviškis, Švenčionys, Pakruojis, Kaunas city, Šiauliai city
2019	3	6	18	Kaunas city, Marijampolė
2020	2		20	Rokiškis, Vilnius city
2021	5	6	37	Tauragė, Kalvarija, Marijampolė, Rokiškis, Kaunas city
2022	4		40	Ukmergė, Zarasai, Ignalina, Kretinga
Total:	41	48	267	22 municipalities

As can be seen from the planned results, the main focus was on the development of GLH, where 10 people with disabilities would be accommodated in one house. It is important to note that the establishment of GLH (from the funds of the state budget) is implemented by the institutional care institutions themselves. Meanwhile, GLH, which are established with EU funds, will be transferred to the activities of non-governmental organizations. On the one hand, in the case when GLH are established by SCI, there is a high risk of trans-institutionalization, but in terms of housing people, this process seems more humane, because people and social work stuff with close social ties are accommodated in new homes. In the case when a NGO starts the activity of a GLH, there are big problems regarding the accommodation of PWD when there is uncertainty, lack of familiarity with individuals, lack of cooperation.

Group living homes

Regarding DI in the sense of piloting and development of services, it can be stated that many different services have been tested - accommodation in sheltered housing and GLH, supported decision-making, social workshops, employment with support, personal assistance, temporary respite services.

Despite the fact that DI encompasses a relatively wide range of services, GLH are the most talked about, criticized the most, expanded the most, and have the clearest continuity (in the way the SCI closure is understandable). Perhaps this is the answer, since the only task set by DI is to reduce the network of SCI.

However, it is very important here to talk about the practices, experiences and content of GLH. First, GLH receive varying levels of support from NGOs. NGOs that advocate the rights of people with disabilities are more critical of GLH than NGOs that provide services. Relatives of PWD would also like their children to live not alone, but with friends. A local NGO wants to get involved in the implementation of GLH development and develop services for its community members to live in a community environment rather than in SCI. Taking this into account, Lithuania is in great need of recommendations regarding the development of GLH, both in terms of scope and content.

Freedom of choice and control of life

PWD living in institutions moved into the first GLH. The former institutions of social care remained the founders and service providers of group living. According to the administrations and employees of the SCI, many people did not want to move to the new homes, because they were used to the environment of the institutions - it was the only home for them. Nevertheless, the vast majority of GLH residents were satisfied with their new home: the environment, activities, new duties and responsibilities, increased independence skills. According to the data of one study conducted in 2020[6] (the sample of which consisted of 13 GLH and 6 SH), PWD evaluate their move to GLH and SH favorably. Here they feel freer, less constrained, more relaxed, safer, calmer. Life at GLH improves the general emotional state of PWD, strengthens independence, increases self-confidence, and expands the field of communication. Life in SH increases the sense of security of residents with mental disabilities, improves health care, promotes independence, and strengthens self-confidence and trust in others. As a result of these changes, the quality of life of individuals improves and the possibilities of integration into the community increase. So, although it seems that people are being transferred against their will, they are happy with the changed life. Nevertheless, in Lithuania, this topic of freedom of choice is very escalating, so it would be useful to have a tool that would allow for country to assess a person's will and desire. Although people with severe disabilities are not accommodated in GLH, the issue of expressing their will is also relevant.

[6] UAB „BGI Consulting" ir UAB „Contextus" (2020). Evaluation report of phase I of the transformation of institutional care: https://pertvarka.lt/institucines-globos-pertvarkos-i-etapo-vertinimo-ataskaita/

The table below summarizes the results of the previously mentioned research, which reveals the lives of PWD through the areas of needs and rights.

I. Areas of need:	**RESEARCH RESULTS**
Health care	The health status and health care of GHL clients have improved due to the improved psychological climate after settling in GLH, better access to personal health care services and taking responsibility for their own health.
Strengthening of independence	The independence of PWD living in GLH has improved due to the increase in self-confidence, the emergence of new responsibilities and the improvement of the ability to plan. However, the independence of PWD is not fully promoted. Although GLH residents receive various responsibilities to promote their autonomy and responsibility, the agenda is generally shared by all GLH residents.
Social integration	The relations between residents of GLH have improved due to the small number of residents, closer communication and common handling of the challenges of everyday life. The relations of residents of GGN with social workers and their assistants have improved due to closer communication with each other. A third of the residents of GGN do not have relatives or their relations with them have been broken, so the desire to restore and maintain relations with relatives is characteristic of a frequent GLH ward. Residents of GLH heavily participate in community and neighborhood processes, although in some municipalities or precincts they receive help from local authorities. The relationship of residents of GGN with their neighbors and community is favorable, although preconceived negative public attitudes towards the PWD prevail, biased presentation of information in the media and general lack of information about this target group. Most residents of GLH tend to communicate mostly with each other, with residents of other GLH and local disability organizations.
Work rehabilitation	Opportunities to work or learn a profession are mainly available to residents of large cities. Residents of GLH have been given the opportunity to participate in professional rehabilitation programs, but the programs are more focused on persons with physical disabilities - there is a lack of work rehabilitation services for persons with mental and/or mental disabilities. In

	addition, some vocational rehabilitation programs do not meet the needs of the modern labor market, so the acquired knowledge and skills remain unapplied.
II. Rights:	**RESEARCH RESULTS**
The right to choose a place of residence	The right of residents of GLH to choose their place of residence is not fully ensured. They are given the opportunity to choose whether to move to the community or to stay in a SCI, but they are not given the opportunity to settle in GLH established by other SCI or use other supported accommodation services in the community.
Right to work	The right to work and fair wages for the residents of GLH is not fully ensured. The supply of jobs where people with partial working capacity could work is not large. Most often, these are unskilled, low-paid jobs.
The right to use the services	Residents of GLH are guaranteed the right to use services both within GLH and in the community. They are informed about the services provided in the community and can choose which activities to participate in. Residents use more diverse services. Residents of GLH located in large cities are guaranteed a greater range of services and easier access to them.

Group living home template

The experience of GLH also shows that they accommodate the most independent residents of care institutions who entered them for various reasons - homelessness, disability, loss of parental care, etc. Meanwhile, the country's legal acts emphasize that GLH are intended only for non-independent or severely disabled persons with disabilities, but this place shows the opposite practice, which in itself presupposes and supports the idea that the place of people with severe disabilities is in large SCI. It is necessary to change this approach - people who can live in the community with assistance should be given the conditions to live in sheltered housing, and people who need intensive care should be accommodated in community-type homes. ,,Mental Health Perspectives" (2022)[7] emphasizes that GLH should only be used as a stopover towards independent living. GLH must focus on improving individuals' daily living skills and expectations. It is especially important to help a person to get a job, support himself, and learn throughout his life, if such a need is expressed. In order to create inclusive services, GLH should not be developed as the main tool of DI. This service does not ensure a person's

[7] ,,Perspectives on Mental Health" (2022). Development of community services for persons with intellectual and/or psychosocial disabilities. Overview of the situation in Lithuania and recommendations: https://perspektyvos.org/veikla/leidiniai/

full right to choose where and with whom to live, it does not provide the opportunity to receive individualized personal assistance, it is limited by such norms as, for example, generally established hours of assistance.

The pattern of group living homes is characterized by the fact that there are usually 10 people with disabilities living in them - only in rare cases is the needs of residents and employees taken into account. Therefore, it is necessary to change the concept of GLH by moving to a smaller number of persons. As the experience of established GLH has shown, a significant number of residents still use institutional and cultural services, for example, individuals go to get a haircut from a hairdresser working in a former institution, or a hairdresser comes to a GLH to cut residents' hair. Residents of GLH do not go shopping in community stores, food is provided centrally from former facilities, or residents are bought by GLH staff. Such examples show that there is a transfer of institutional culture to newly established homes, so it is necessary to invest in the development of employees' competencies, changing work methods from an institutional to a community and human rights-based approach.

As already mentioned, GLH face the risk of trans-institutionalization and transfer of institutional culture, which is characterized by social distance, strict order and routine. Social workers and their assistants working in GLH become responsible for a group of people, but services are also provided and organized for them on a group basis - cooking, spending free time, daily schedule. Thus, there is a great lack of content and personal individuality in group living homes. For example, residents of group living homes attend social workshops during the day, where they all do one and the same craft together. Maybe someone, depending on their individual needs, would like and be able to attend other activities, e.g. In the NGO day center, maybe someone could get a job in the open labor market, contribute to various social activities, etc., but in this aspect, group life homes are stagnant - they are dominated by group perception of free time, responsibility and plans. Raising the competences of social workers, using volunteers and other community members could help in this area. Intersectoral cooperation is also important, for example employment service specialists could organize all kinds of assistance to the person.

Service development results

In 2020 - 2023, the DDA implements the project "From care to opportunities: development of community-based services", which tests and provides 4 services: supported decision making, employment with support, accommodation in sheltered housing and social workshops. Since the

beginning of the project, supported decision making services has been received by 500 persons, employment with support – 393, accommodation in sheltered housing – 222, social workshops – 598.

Supported decision making. The purpose of the service is to strengthen a person's ability to take care of himself and make daily decisions with the help of a decision-making assistant or a team of specialists in order to achieve independent living and participation in all areas of life. Assistance in decision-making is a personal decision-making process, when the person making the decision uses the help of a specialist or a team of specialists (2-5 persons) who help him. The specialist together with the recipient of this service solves various everyday issues - health, social participation, assets, etc. It is important to note that decisions are primarily based on the will, wishes and right of choice of the person making the decision.

Employment with support. The purpose of the service is to help a person of working age who is willing and able to work in the open labor market, but due to the nature of his disability or the prevailing discrimination in society, cannot find a job and establish himself in the open labor market.

An assisted employment specialist helps a specific person find a suitable and pleasant job according to his abilities and market opportunities, and also provides him with further assistance in establishing himself in the workplace.

Accommodation in sheltered housing. Sheltered housing provides counselling, mediation, social skills development and support services, and a place to live in the community for partially independent adults with mental disabilities. Up to four adults can live in the rented apartment. They are provided with individual assistance from a case manager - a social worker. These people receive other services in the community. In this way, people's social and independent life skills are developed and supported in order to achieve complete independence.

Social workshops. The purpose of social workshops is to increase the employment opportunities of people with intellectual or psychosocial disabilities in the open labor market, to develop and maintain general and special work skills by performing meaningful employment activities aimed at the production of a specific product, product or service. The social workshop service is provided to people from the age of 18 who, due to certain reasons related to their disability, cannot get a job in the free labor market or use the assisted employment service. When providing this service, work with visitors to social workshops is organized according to individual plans, taking into account the abilities and opportunities of each person. The service is organized according to the principles of person orientation, activation, adequacy, partnership, work orientation, and social entrepreneurship.

One of the more important features of social workshops is the production of competitive and high-quality products, after the realization of which a person receives a certain reward or is otherwise encouraged and motivated.

Summarizing all four services, it can be said that their meaning and purpose are aimed at increasing the independence of individuals and preventing institutional care. Many of these service providers are non-governmental organizations. The pluses are that they are not only closest to people and provide services, but they are also gradually changing their activity profile, as new and innovative services are provided. NGO are selected on a competitive basis. The biggest risk of service provision is that service provision, both from the point of view of NGOs and municipalities, is viewed as individual project activities - there is no thought about their continuity, there is a lack of legal regulation, service analysis. There are quite a few cases where municipalities are not involved in the provision of services at all and issues regarding the continuity of services are assumed as a financial burden for the municipality. Based on the experience of various projects, it is very important to provide such an algorithm that would oblige municipalities to participate in projects from the beginning, analyze the benefits of services, help NGOs solve emerging problems, etc.

POSITIVE DI PROCESS CHANGES

- What has been successful throughout the change process

Within the framework of DI projects, *personal assistance*, *temporary respite* and *sheltered housing* services were piloted in Lithuania, which later became regulated at the legislative level, which means that these services must be available and guaranteed to all people with disabilities and their relatives as needed.

- As regulated by the Law on the Social Integration of the Disabled, Personal assistance is the individual assistance provided by a personal assistant to a disabled person to perform tasks and perform activities that he cannot perform independently due to his disability and which are necessary in order to live independently and function in all areas of life. The amount of the disabled person's payment for personal assistance cannot exceed 20 percent of the cost of providing personal assistance and cannot exceed 20 percent of the disabled person's income, determined and calculated in accordance with Article 30 of the Law on Social Services. Personal assistance is provided free of charge to a disabled person whose income is lower than 2 times the amount of state-supported income.

- It is planned that in 2023 the newly enacted social services law will regulate the temporary respite service. Temporary respite is assistance to a person who daily cares for a person who has been identified with special needs of permanent care, providing an opportunity to rest. Temporary respite will be provided free of charge.
- Sheltered housing was also one of the services piloted during the DI process, which was later (in 2019) regulated in the Social Services Catalog. Sheltered housing is described as accommodation and assistance in a home environment, organization of necessary services in the community, in order to compensate, restore, develop, support and develop a person's social and independent life skills. PWD and their families, persons experiencing social risk (who need relapse prevention assistance), adults who have been provided with institutional social care or who lived in families experiencing social risk (up to 24 years) can receive this service. It is envisaged that the service will be provided to PWD and their families, accommodation for up to 3 years or longer, assistance - from 1 to 10 hours per week.

- What is not going well - where are the biggest barriers in the change process, in which area (e.g. strategy - understanding the purpose of change; managing change, attitudes of service leadership; identifying people's needs and preparing people for change, guiding them through change; working with staff; funding for change, public insights and attitudes...anything where you see a barrier).

One of the biggest barriers is a lack of understanding of the concept of DI. The most common perception is that DI represents a shift from service delivery in large inpatient facilities to smaller infrastructural segments in the community. However, such a concept of DI does not include changes in the rights of service recipients. GLH face a high risk of trans-institutionalization and transmission of „institutional culture", which main features are group supervision, strict order and social distancing. Although, as regulated in the country's legal framework, GLH are intended for completely non-independent persons, but in practice, the most independent residents of the institutions are transferred to them.

The successful implementation of the DI process depends on the cooperation between many sectors and actors: ministries, municipalities, non-governmental organizations, social service organizations. However, between these different levels, there is a predominance of conflict, mistrust of each other, selfishness, etc. For example, in the opinion of municipalities, DI is a problem of the ministry, because it aims to transfer persons from state care institutions to communities. These people are treated as "state" people, not "municipalities" people, so housing these people becomes a problem for

municipalities both due to the lack of services and the communities' resistance to the neighborhood of PWD.

PWD participate in the DI as objects - recipients of new community services. There is no mechanism to involve PWD themselves in policy planning, decision-making, monitoring and control. Not including people with disabilities in the DI means that the process itself is affected by the medical model of disability, because PWD do not participate in it, and their lives are decided by other participants in the DI, making decisions about how many and what services this group of people needs.

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

In the implementation of DI, there is a lack of attitude that problems or challenges faced by an individual or family must be solved proactively. It is estimated that social care institutions are usually approached for accommodation because there are no more relatives left who could help a person with a disability who needs care to live in their own home, or it becomes too difficult for the relatives physically, emotionally and economically, they experience burnout and overwork. This shows systemic gaps and a large gap in the lack of services in the community when maneuvering between informal and institutional care. Families lack access to information about available services, their types and variety.

There is a lack of services that are differentiated according to the characteristics of the disability. For example, severe disability cases or services for people with autism spectrum disorder.

- What tools are available in the country and how they are used, how functional they are (e.g. from the country's legislation supporting DI, other support strategies to other methodological tools). A preview of the results of their use (what works, what doesn't, what needs to be different).

The norms of social care, approved by the order of the MoSSL, establish that from 2030, long-term social care for adults with disabilities cannot be newly provided in SCI for adults with disabilities, with the exception of specialized nursing homes and social care homes. SCI for adults with disabilities

no later than 2028 (January 1) must approve the plans of measures agreed with the institution implementing the rights and duties of the owner of the institution, the implementation of which will achieve the requirement to no longer provide long-term social care to adults with disabilities in these homes from 2030. This legal provision states that from 2030, PWD will no longer be able to enter SCI, except in very difficult cases. This provision aims to involve municipalities in the planning of alternative services to institutional care.

Transformation action plan is a document that defines the goals, objectives, indicators, sources of funding, responsibilities of DI implementation, but in practice this legal act is simply a basis for the use of EU funds.

- Identification of what partners would need - description of needs from the perspective of people with disabilities, from the perspectives of organisations, service providers. Which can then be targeted and addressed in the development of the Guide and training programme.

There is a critical need for the country to have a methodical policy-making system that includes with PWD, their relatives, the NGO sector, local government, the ministry. There should be a procedure that when making one or another decision, regardless of whether the ministry or municipality is responsible for it, a sequence of works must be done that would respond to the slogan ,,Nothing about us without us". A procedure for analysis, decision-making and their justification should be created.

There is a need for a case management mechanism that would unite the services of the different sectors - social, health, employment, justice, education and other systems. Currently, a person (family) has to go through the doors of many institutions in search of help. Help must come to the person. Support needs must be identified as early as possible so that the person does not experience social exclusion and problems in the future. It is not a good practice that in the country, assistance to a person is organized between informal family care or life in large care institutions. Deinstitutionalization must begin with the identification of the fact of disability, whether it occurs at birth, in childhood or later in life. Proactive and timely support can build independence for individuals, support families and keep individuals in the community.

- What is the experience of active participation in change by people using the service, their relatives.

Service users

PWD are the main group of persons for which the DI is being implemented. The preamble of the Convention states that PWD should actively participate in decision-making on policies and programs,

including those directly related to them. However, Lithuanian experts agree that informing PWD about new community services is one of the weakest areas of implementation of the DI. Lithuanian researchers noted this back in 2015: "In the social care system, information about the transformation is disposed of on a hierarchical principle: the administration of the institution mostly decide what and how to tell the employees of the SCI, and they, in turn, provide the information to the clients of the institutions" (Mental health perspectives, 2015[8]). The "voice" of PWD, like the DI itself, should be seen from two perspectives, including PWD who live in institutions and those who live in the community. It is important to note that the opinions of PWD are greatly influenced by the opinions of employees who work directly with them. Due to the closed system of institutional care and the remoteness of institutions, staff are the ones who convey basic information to clients. Finally, it is agreed that the inclusion of people living in care institutions in the planning and evaluation of processes is understood too narrowly. Residents' councils operate in care institutions, but their decisions often do not go beyond the boundaries of the institutions. The only contact of SCI residents with the "outside" world was the assessment of the individual needs of PWD, which was carried out by independent experts and allowed to hear the opinions of these people. However, such an expression of participation is limited and subject to criticism, showing a narrow understanding of the right of PWD to participate in decision-making. PWD could speak only about the motivation to move to other community-type services, which cannot in any way be related to the real inclusion of PWD and the right to make decisions.

Relatives

Since the DI was based on institutionalized individuals, most of whom no longer have any ties to their relatives, relatives were not involved in policy planning in any way. However, parents of children with disabilities who do not receive any help in raising children with disabilities are starting to speak out more and more recently in Lithuania. Families are increasingly calling for public assistance to avoid feeling overwhelmed and burned out, to participate in the labor market, to avoid having to care for their minor or adult children with disabilities for hall day and night. The Forum of Lithuanian disability organizations began to actively mobilize mothers and fathers so that the state would take changes and plan support for families who care for children with disabilities. This movement led to the regulation of temporary respite care so that every family would have the right to

[8] Psichikos sveikatos perspektyvos. (2015). Gyvenimas savarankiškai ir įtrauktis į bendruomenę. JT neįgaliųjų teisių konvencijos 19 straipsnio įgyvendinimo Lietuvos socialinės globos sistemoje stebėsenos ataskaita. Prieiga per internetą: http://www.perspektyvos.org/images/failai/gyvenimassavarankiskai_ataskait a.pdf

take a break from the constant care of family member. According to the director of the administration of the Lithuanian disability organizations Forum, a study was conducted that showed that in Lithuania, parents raising children with severe disabilities spend an average of 14 hours a day looking after them, while in Sweden it is 8 hours a week, in Norway – 12 hours a week. Families lack intersectoral assistance and services that would be ensured from the birth of a person with a disability. Inaccessibility of information, different responsibilities of different organizations do not ensure the arrival of help to families, families have to look for help themselves.

The table below presents data on the attitudes of PWD who enter and leave institutions.

Year	Entered SCI	Settled in the community (not GLH or other)
2019	681	41
2020	678	No data

FUTURE PLANS

Currently, Lithuania is intensively preparing for the new EU investment period, which will be financed in 2021-2027 with EU structural funds. Accordingly, this stage is referred to as Stage II of DI. It can be noted that the future plans are significantly different from the previous period. The main differences:

PLANNING. At the end of the year 2021, the MoSSL provided all the country's municipalities with guidelines for the preparation of the Transition from institutional care to family and community services map (hereinafter referred to as the Map). The strategic goal of the Transition from institutional care to services provided in the family and community Map is to prepare a strategy for the DI of care for PWS, on the basis of which an even, sustainable and human rights-based transition from institutional care to services provided in the family and community will be implemented in the regions. Municipalities were asked to include local NGOs working in the field of mental and/or intellectual disability in the process of preparing the Map. Thus, one of the key differences in planning is that it sought to identify the needs of PWD living in the community. Needs were identified in the areas of accommodation, day employment and temporary respite, so the planning also included relatives of PWD living in the community, who constantly care for a relative with a disability. Also, in order for the identification to include as many persons in need of assistance as possible,

municipalities were asked to find persons and families in need of assistance through the social workers of the elderships.

So the main differences in planning, 2014-2020 during the EU funding period, the needs of the social care population were resisted, and in 2021-2027 - from the needs of PWD living in the community.

DI TERRITORIAL EXTENT. In the past period, DI was implemented in 6 out of 10 regions of the country. The regions were selected according to the restructuring SCI, but as mentioned earlier, not all municipalities wanted to develop various services in their territory. Where the municipalities refused to participate, institutions under the MoSSL established the infrastructure in their place. The MoSSL was also responsible for the preparation of investment projects and the distribution of finances.

In the new period, the regions are responsible for the establishment of infrastructure, which themselves plan where and how to spend the funds. Assessing the risk that the DI of the care of PWD was never a priority, the MoSSL mandated that the prepared Maps must be implemented. Therefore, the Map became the main tool to control the involvement of municipalities in the implementation of services. By the way, if the region refuses to implement the Map, the region loses the right to use the funds that can be allocated to the social area, therefore the implementation of the map is a necessary condition.

PLANNED SERVICES.

As summarized in the infrastructure results section, in the period of 2014-2020 it was planned to establish 115 infrastructure facilities: 6 (40 places) specialized social care and nursing homes, 68 GLH, 3 independent living homes, 8 sheltered dwellings, 2 day centers, 14 day centers/social workshops and 14 social workshops. In the new period, it is planned to significantly expand the sheltered housing service. According to the regional Maps, it is planned to establish 321 sheltered housing units throughout Lithuania, where 642 persons with disabilities will be able to live. It is also planned to further develop GLH activities by establishing 85 GLHs, where about 850 PWD will be able to live. It is planned to create about 1600 places for daily employment (in social workshops or day care centers).