



SURVEY ON DEINSTITUTIONALIZATION PRACTICES IN LITHUANIA

The survey was carried out within the framework of the project "Towards efficient sustainable transition in social care".

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The survey was performed by Lithuanian welfare society of persons with intellectual disability "Viltis", Lithuania.

Main project partner: Centrum podpori transformace, o.p.s., Czech Republic.

Project partners: Centrum podpori transformace, o.p.s., Czech Republic; Inclusion Europe, Belgium; Fundatia de Abilitare Speranta, Romania; Social Work Advisory Board, Slovakia; Lithuanian welfare society of persons with intellectual disability "Viltis", Lithuania.

Time of performing the survey: January-February, 2023.

Lithuanian welfare society of persons with intellectual disability "Viltis" carried out a qualitative survey in order to find out what good experiences can be shared by institutions and organizations participating in the deinstitutionalization (hereinafter DI process) process in Lithuania. During the survey, 8 organizations were interviewed. Type of survey - questionnaire: anonymous questionnaire (consulting the participants of the deinstitutionalization in case of ambiguities or to clarify some answers).

1. Survey results

1. Organizations from the following municipalities participated in the survey: Kalvarija municipality (1 participant); Kaunas city municipalities (3 participants); Marijampole municipalities (1 participant); Municipality of Pakruojis district (1 participant); Municipality of Radviliskis district (1 participant); Taurage district municipality (1 participant); Tarkai district municipality (1 participant); Vilnius city municipality (1 participant). It is important to note that the deinstitutionalisation did not take place on the scale of the whole of Lithuania, but only in six (Vilnius, Kaunas, Siauliai, Marijampole, Telsiai and Taurage) regions¹.
2. The DI process in Lithuania² even had several possible options: social workshops, sheltered housing, supported decision making, assistance in employment and other services that give a

¹ GENIENĖ, R. DOCTORAL DISSERTATION: Development and provision of social services to persons with psychosocial disabilities in the perspective of social care reform.

² See Implementation measure of priority 8 "Increasing social inclusion and fighting poverty" of the 2014-2020 European Union funds investment action program no. 08.4.1-ESFA-V-405 "Transformation of Institutional Care" project financing conditions description no. 3.

disabled person the opportunity to live in the community, so the participants of the survey were given the opportunity not only to choose the answers, but also to record themselves

which services they chose to provide in the community (in the context of the DI process). It is also important to emphasize that one organization can carry out several DI projects. For example: providing a supported decision-making service while preparing for the provision of a group living home service together. The organizations provided the following services: sheltered housing (4 services provided), independent living homes (2 services provided), social rehabilitation center services (2 services provided), group living homes (3 services provided), supported decision-making (3 services provided), assisted employment (2 services provided), social workshops (1 service provided). It can be assumed that the organizations that participated in the survey provide 2 services on average.

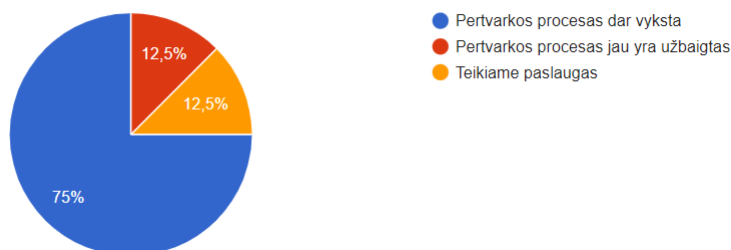
Picture Nr.1.

Construction of group living houses in Trakai district municipality. January 2023



**3. Picture no. 2 shows the distribution of respondents to the question:
"What stage of the DI process is your organization in?"**

Three possible answers options have been given to the respondents: the DI process is still ongoing, the DI process is completing, and a freely chosen/recorded answer option. About 75 percent of respondents have answered that the DI process is still ongoing in their organization, for example, the group living homes are still under construction, setting up sheltered housing, etc. 12.5 percent of those surveyed have indicated that the DI process in the organization has already been completed. 12.5 percent of respondents have indicated that service is provided. This answer option was a free-choice and can therefore be collectively classified as the answer "the DI process is already completed" because the completion of the process implies the provision of services. To resume, it should be noted that 75 percent of the surveyed organizations have responded that the DI process is still ongoing, and 25 percent of the surveyed organizations have responded that the process is completed and the community services are provided.



2 Picture. Diagram

4. Question to the Survey participants:

a) What is your opinion about the goals of the DI process and why does your organization participate in the DI process?

Attention should be drawn to the 2012 November 16 No. A1-517 Order of the Minister of Social Security and Labour³ (hereinafter - Order), which states that in 2010 Lithuania ratified the United Nations Convention on the Rights of Persons with Disabilities (hereinafter - the Convention) and its Optional Protocol, which was approved by the Law of the Republic of Lithuania on the United Nations Convention on the Rights of Persons with Disabilities and ratification of its Optional Protocol. [...] States that have ratified the Convention, including Lithuania, recognize the equal rights of all disabled people to live in the community, equal opportunities to choose and take effective and appropriate measures to enable disabled people to fully realize this right and be fully included in the community and participate in it, would also ensure that disabled people have the opportunity to choose the place where they want to live and with whom, on an equal basis with other persons, and that they are not obliged to live in a specific residential environment.

As named in the order of 2014 February 14 of the Minister of Social Security and Labour (hereinafter - the Plan⁴), the strategic goal is to create a system of comprehensively provided services that would create opportunities for every child, disabled person or their family (guardians, caregivers) to receive individual services and necessary help in the community, and for everyone without parental care for the child to grow up in a safe and favourable environment in the biological family, in its absence - in the family of adoptive parents or guardians. The plan has 3 goals. The first goal of the Plan is to

³ 2012 November 16 Order of the Minister of Social Security and Labour of the Republic of Lithuania no. A1-517 "On approval of strategic guidelines for deinstitutionalization of social care homes for disabled children, children left without parental care, adult disabled persons".

⁴ 2014 February 14 Order of the Minister of Social Security and Labour of the Republic of Lithuania no. A1-83 "On the approval of the 2014-2020 action plan for the transition from institutional care to family and community-based services for disabled children and children left without parental care".

ensure a harmonious environment and conditions for every child (and a disabled child) to grow up in their own family, and for the remaining children without parental care to grow up in the family of guardians, adoptive parents or families and receive help in the community. The second goal of the Plan is to create conditions for disabled adults and their families (guardians, caregivers) to receive individual community services that meet their needs. The third objective of the Plan is to promote a change of society's value, forming a positive public attitude of the society towards the transformation

of the system, and to ensure the publicity of the ongoing processes. The second and third objectives of the Plan are relevant to this phase of the survey.

The respondents named the following goals of the DI process:

- 1) Change institutional services to alternative services in the community, so that the choice of services is as diverse as possible.
- 2) Better quality of life for people with disabilities.
- 3) The purpose of the DI process is to create conditions and provide services for a disabled person or his family in the community, taking into account the individual needs of each person. Create living conditions that meet the abilities of a person with disability (choice of services).
- 4) To meet the needs of people with disabilities and dignified living (not existence) conditions, ensuring their rights.
- 5) Better inclusion of persons with disabilities into the life of community.
- 6) Integration of persons with disabilities.
- 7) Providing services in the community.
- 8) Implement Article 19 of the UN Convention on Natural Resources: "Living independently and joining the community".

The answers given by the survey participants show that there is a clear understanding of the reasons for deinstitutionalization in Lithuania. One direct answer and indirect answers name the United Nations Convention on the Rights of Persons with Disabilities Article 19, i.e. inclusion of persons with disabilities in the community. The answers reveal the perception of specialists about the deep social problems of persons with disabilities existing in Lithuania. For example: answer no. 4 (and no. 2) shows the respondents' understanding that in Lithuania persons with disabilities live in large institutions, where it is much more difficult to ensure dignified living conditions than in small organizations. Answers no. 1, 3, 5, 6, 7, 8 testify about the integration of persons with disabilities in communities, showing another relevant problem of Lithuania - segregation of persons with disabilities. Often, during the Soviet era, large social care homes were built far from residential areas - large cities and towns. This is one of the reasons for segregation and the inability to use community services available to other persons without disabilities. Answer no. 3 indicates another important goal of social services (including in the DI process) - individualization of services⁵. The DI process in Lithuania gave the opportunity to choose different types of services for persons with disabilities. For example: depending on the person's abilities, different forms of accommodation with support are

⁵ See Description of the methodology for the provision of services for adults with (mental and/or mental) disabilities in the form of assisted living, Independent Living Home Services. Online access: <https://pertvarka.lt/wp-content/uploads/2022/02/SGN-aprasas.pdf>

possible: group living homes (Residents of group living homes receive necessary services at home full-time and use other community services), independent living homes (providing minor assistance to compensate for the loss of (lack of) independent living life skills) and sheltered housing (combining accommodation services with individual case manager (social worker) assistance and other services in the geographic community). A person with a disability who has chosen to live in a group living

home and has acquired the necessary skills can move to an independent living home and then to a sheltered housing.

This survey question did not discuss the purpose of the 3rd DI process Plan - to promote a change in society's values and to form a positive attitude towards the transformation process and to publicize the progress of the process. However, this objective will be revealed in the context of other questions.

It is interesting to review the reasons behind the respondents' choice to participate in the DI process: to enable persons with disabilities to live with dignity in the community.

Therefore, it can be concluded that the specialists participating in the DI process understood the fundamental goal of the DI process - the integration of persons with disabilities into the community.

b) What good experience can you share with other institutions planning to carry out the DI process.

The absolute majority of respondents indicated that there is a need to provide more decision-making opportunities for persons with disabilities. Some of the respondents emphasized that the empowerment of persons with disabilities in the DI process must take place with the help of specialists; some of the survey participants identified the need for relatives of persons with disabilities to participate in the process. This approach is welcomed. The opinion is supported that persons with disabilities should get help from professionals to use their rights and to exercise them (in terms of rights which they cannot exercise independently).

Respondents indicated the need to strengthen relations with the institutions involved in the DI process - the Ministry carrying out the DI process, the municipality where the DI process is taking place, guardianship institutions.

The need for more cooperation with the local community and more active publicizing of the ongoing DI process (including within the community itself) was also emphasized. It is appropriate to connect this answer with society's stereotypes and negative attitude towards people with disabilities (in particular, towards people with psychosocial disabilities or impaired intelligence). This statement is reasonable, taking into account the conflicts that have arisen in the construction of communal houses for persons with disabilities. In Lithuania, the case in Žiežmariai⁶, in the municipality of Kaišiadorių district, when the local community opposed the accommodation of persons with disabilities in their community⁷, became particularly widespread. The then Minister of Social Security and Labour of the Republic of Lithuania was involved in the resolution of the conflict.

⁶V., GEVORGIANIENĖ, E. ŠUMSKIENĖ, J., MATAITYTĖ-DIRŽIENĖ, R., GENIENĖ. "People and Places: Social and Physical Aspects of Life for People with Disabilities in the Community." Vilnius University, Lithuania

⁷ Look at: <https://www.delfi.lt/news/daily/lithuania/garsioji-ziezmariau-bendruomene-vel-kyla-i-kova-neigaliuju-apgyvendinimo-aplinkybes-nuo-musu-nusleptos.d?id=84762969>.

So, it can be stated that it is necessary to include more persons with disabilities in the deinstitutionalization processes (if it is necessary to provide them with assistance), to strengthen relations with such institutions as the Ministry carrying out the transformation, the municipality where the DI process is taking place, social care homes whose residents participate in the DI process, local communities in which the DI processes are taking place directly. It is important to publicize and

inform the public about the ongoing deinstitutionalization processes, thus destroying stereotypes and negative attitudes towards persons with disabilities.

c) What is justified in the DI process, and what should be done differently?

The respondents did not give a unanimous answer on this issue. It can be assumed that the difference in answers may be due to different experiences in the regions where the DI process took place/ or is still going on. For example, the willingness of municipalities to cooperate, society's attitude towards persons with disabilities.

The participants drew attention to the following aspects (summarized answers are presented):

- Before carrying out the DI, it should be paid more attention to the good experiences, scientific survey and recommendations of foreign countries.
- It is necessary to firmly represent the interests of disabled people so that services are not distorted, their content and quality are not affected.
- A person with a disability must be able to choose the service he wants to receive. Persons who live the whole life in inpatient institutions do not fit into society.
- During the structural and planning processes (buying a house, adaptation, etc.), we realized how long "official" work takes (coordinating with institutions, lawyers, public procurement, etc.), so it is a very short time left for direct implementation (selection of people, preparation, etc). As a result, the implementation of the DI process becomes complicated. It is alarming that the priority is given to documents, and not to direct work with people receiving these services.
- It is difficult to reduce the social gap between disabled people and society. It receives positive attention and support from local government representatives, they are interested in how this service is managed and how the lives of service recipients are changing. But the most important thing is that during the DI process, individuals are able to achieve the greatest change and this brings visible results.
- It has been justified that both people from the community and institutions were accepted for the services. This is a real integration. The provision of services to persons with intellectual and mental disabilities together in social workshops has not been justified.
- When budgeting DI process works in general, it should be taken into account that the process itself may become more expensive due to inflation. Additional budget can be required. The Ministry did it. To pay more attention to informing the population about what the DI process is, the goal of DI process, for example, the construction of the Group living home, etc.

Attention should be drawn to the following aspect: a person who lived in a social care home all his life, does not fit in to live for example, in a group living home. This is determined by several important factors: persons living in social care homes are not taught independence, i.e. basic housework such as: washing, cooking, cleaning, etc. This is understandable, because in large care homes with 200 or more service recipients, it is not physically possible to provide life skills training. Another important factor is attachment to the environment where a person lived for 10, 20 or even 30 years and social relations with other residents of social care homes, relatives living in that area or even employees. It should not be considered a case of failure, but rather the absence of certain alternatives to social

services in the past (for example, 2012 yr. is considered the turning point of the DI process in Lithuania; until that time there were no alternative life options, except for a few private initiatives⁸). According to the surveyor's knowledge, there are not so many cases in Lithuania when a person has moved to live in, for example, to a group living home and returns to live in a social care home). However, such cases do exist and therefore it is important to keep this in mind when carrying out the deinstitutionalization.

The need for an additional budget. The remark is justified because, for example, in Lithuania on October⁹, 2022 inflation reached as much as 22 percent.

It should be taken into account that before carrying out the deinstitutionalization process, more attention should be paid to good experiences of foreign countries, scientific survey and recommendations; strive to preserve the quality of services provided in newly reorganized organizations, pay more attention not to deinstitutionalization documentation, but to work with persons with disabilities preparing them for a new method of providing social services; enable persons with disabilities to choose services suitable for them; to differentiate the services provided for different disabilities; provide a reserve in the deinstitutionalization budget.



3 Picture. Construction of group living houses in Taurage district municipality, group living houses are administered by Adakavos Social Services House. Summer 2019.

⁸ Look at: <https://www.betzata.lt/istorija> . It is a community based on Catholic values. Founded in Lithuania in 2004.

⁹ Look at: <https://www.vz.lt/finansai-apskaita/2022/10/28/spali-infliacija-lietuvoje-sieke-22>.

d) What positive aspects of the DI process can you name?

The respondents were quite unanimous when answering this question in a free form. The absolute majority emphasized - increasing the independence of persons with disabilities (including participation in the labour market), improvement of their quality of life, involvement in the local community. Some respondents also identified the following aspects: the development of care institution partnership and receiving services outside social care homes, the need to further reduce the number of organizations where individuals receive services in future. It also encountered negative

feedback: "Persons with disabilities are not yet participating in this process, so the only positive moment of the DI so far is that it is taking place and funding is being allocated."

Conclusion about positive aspects of the DI: increased independence of persons with disabilities, improvement of their quality of life and involvement in the local community.

e) Do you think that the goal of the DI process has been achieved? Please justify.

It was possible to choose several answer options: 1) Yes, it has been achieved. 2) No, it has been achieved. 3) Partially achieved. 4) Other, allowing the respondents to independently record the answer or explain the reason for choosing one or another answer.

When choosing the answer "partly", some participants justified their answer with the following arguments: "Partly, because there was no consistent preparation for it, lack of experience, lack of publicity and still strong negative public opinion about disabled people". This correlates with the unachieved Plan 3 objective, i.e. promote a change in society's values. Some participants indicated "Partially achieved, because not all institutions participated in the DI; many institutions in Lithuania are not involved in the process. We should go further and further reduce group living homes. The best way would be if a disabled person does not live in any institution, no matter how small it is and he/she could get community-based services. In this case it is a need to increase the range of services provided by a personal assistant, etc."

f) What difficulties did you face during the DI process?

The answers were quite unanimous: lack of information (some answers from the responsible authorities were received late or not at all); communities' attitude towards persons with disabilities (negative attitude of local communities, lack of confidence in their abilities to live independently); lack of employee competence; lack of municipal cooperation/sluggish communication.

g) Could you submit any comments about the DI process in Lithuania?

Some of respondents have pointed that each service is very individual, just like the people who need the help. However, they also have emphasized the lack of cooperation between institutions, care institutions, and municipalities, little help from the municipalities. There was a lack of flexibility in implementing the DI process. Concerns are expressed about ensuring continuity of services.

5. Survey conclusions:

5.1. Organizations from the following municipalities participated in the survey: Kalvarija municipality (1 participant); Kaunas city municipalities (3 participants); Marijampole municipalities (1 participant); Municipality of Pakruoj district (1 participant); Municipality of Radviliškis district (1 participant); Tauragė district municipalities (1 participant); Tarkai district municipalities (1 participant); Vilnius city municipalities (1 participant).

5.2. The investigated organizations provided the following services: sheltered housing (4 services provided), independent living homes (2 services provided), social rehabilitation center services (2 services provided), group living homes (3 services provided), decision support (3 services provided

services), employment with support (2 services provided), social workshops (1 service provided). It can be assumed that the organizations participating in the survey provide 2 DI services on average.

5.3. 75 percent of the surveyed organizations answered that the DI process is still ongoing, and in 25 percent of the surveyed organizations respond that the process has been completed and community services are provided.

5.4. Specialists participating in the DI process understood the fundamental goal of the DI process - integration of persons with disabilities into the community.

5.5. It can be asserted that it is necessary to include more persons with disabilities in the deinstitutionalization processes (if it is necessary to provide them with assistance), to strengthen relations with such institutions as the Ministry carrying out the DI process, the municipality where the DI process is taking place, social care homes whose residents participate in the DI process, local communities, which are directly affected by DI process. It is important to publicize and inform the public about the ongoing deinstitutionalization processes, thus destroying stereotypes and negative attitudes towards persons with disabilities.

5.6. Before carrying out the deinstitutionalization process, pay more attention to the good practices, scientific survey and recommendations of foreign countries; strive to preserve the quality of services provided in newly reorganized organizations, pay more attention not to deinstitutionalization documentation, but to work with persons with disabilities preparing them for a new method of providing social services; enable persons with disabilities to choose services suitable for them; to differentiate the services provided for different disabilities; provide a reserve in the deinstitutionalization budget.

5.7. Positive aspects of the transformation include: increased independence of persons with disabilities, improvement of their quality of life and involvement in the local community.

5.8. Not a single respondent stated that the goal of the DI process was not implemented. Respondents indicated that the goal was achieved or partially achieved. The reason why the goal was only partially achieved is stated as the lack of preparation, publicity of the transformation process, negative attitude of the community towards persons with disabilities; and the fact that not all regions of Lithuania participated in the DI process.

5.9. The disadvantages of the DI process are defined as the lack of information; communities' attitude towards persons with disabilities (negative attitude of local communities towards persons with disabilities, lack of confidence in their abilities to live independently); lack of employee's competencies; lack of municipal cooperation/sluggish communication.

