

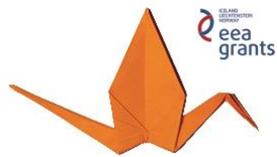


MENTAL
HEALTH
PERSPECTIVES

Independent Living and Community Inclusion

**Monitoring Implementation of
UN CRPD Art. 19 in Lithuanian
Social Care Institutions**





Pokyčių sparnai



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Introduction

Precisely ten years ago, in 2004 and 2005, following being awarded funding by the European Commission and the U.S. Embassy in Lithuania, the representatives of four NGOs (Human Rights Monitoring Institute; “Global Initiative on Psychiatry” (currently “Mental Health Perspectives”); Lithuanian Welfare Society for Persons with Mental Disability „Viltis“; and Vilnius Centre for Psychosocial Rehabilitation) visited eleven social care institutions based in Lithuania. Using a comprehensive questionnaire, a group of experts interviewed the personnel, as well as staff members and current residents of these institutions. As a result, full-scale information on the situation of human rights in the residential social care settings was gathered. Based on this data, various publicity measures were taken in order to raise awareness about the existing issues and gaps in the system, such as presentations to the members of the Lithuanian Parliament and representatives of the Ministry of Social Security and Labour, as well as members of the general public. Also means of the media were used, such as television, press, and the internet. Although these reports did provoke various reactions, systematic changes, including the needed shift from the institutional to community-based care approach, did not begin.

In the following ten years various changes have been implemented on the political level, some of which contributed to the deinstitutionalization processes, while others were merely superficial. Finally, some of the changes contributed to the actual stagnation within the social care system:

- On 3rd April 2007 the Mental Health Strategy was ratified by the Parliament of Lithuania, which included Ensuring the protection of human rights in the mental health system through independent monitoring (especially in the residential facilities). However, the strategy is not being implemented: both the 2008 – 2010 action plan for implementing the strategy and the 2011 – 2013 interinstitutional action plan have not met the two core principles of the strategy as stated in the six fundamental goals: ensuring of the human rights and implementation of systemic changes in the mental health care system. Based on the analysis on mental health improvement and implementation of preventive measures of mental disorders carried out by the researchers, which was to assess the development of Lithuanian mental health system, it seems that most of the measures are not carried out or their implementation is constantly being postponed (Pūras et al., 2013).

- UN Convention on the Rights of Persons with Disabilities and its Optional Protocol were ratified by Lithuania on 27th May 2010. Article 19 “Living independently and being included in the community” states that people with disabilities should have the opportunity to choose their place of residence and where and with whom they live, on an equal basis with others and are not obliged to live in a particular living arrangement.
- Most of the EU funding of the 2007 – 2013 structural funds programming period was dedicated to improving the living conditions in the existing institutions, such as the insulation of walls and roof, improving the heating system or water facilities in Lithuania. These kind of improvements did not address the abuse of the human rights of residents within the social care system in any way, nor did it promote community-based support approach. As a result, it only contributed to the actual consolidation of the existing system.
- In 2012 European Expert Group on the Transition from Institutional to Community-based Care released two reports on the shift from institutional to community care approach: “Common European Guidelines on the Transition from Institutional to Community-based Care” and „Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care“. These documents provide practical recommendations on how to effectively switch from institutional care to community-based care for current residents of institutions as well as for those who are living in the community but lack the needed support. Moreover, recommendations have been made for the governmental institutions of EU member countries which are responsible for the programming and administering of the EU structural funds.
- On 3rd December 2013 the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment was ratified, establishing an obligatory and continual independent monitoring system for preventing human rights abuses in residential institutions. The task was appointed to the Seimas Ombudsman’s Office of the Republic of Lithuania.
- On 16th November 2012 strategic guidelines for Deinstitutionalisation of social care homes for children who have disabilities, children without parental care, and adults with disabilities was ratified by the Minister of Social Security and Labour of Lithuania. On 14th February 2014 action plan for Transition from institutional care to family and community-based care for adults with disabilities and children without parental care over 2014 – 2020 was ratified. It has been planned to implement these measures with the help of 2014 –

2020 EU structural funding which would be obtained by the governmental sectors of various levels (national, regional, and municipal), as well as by NGOs; a certain level of cooperation has been expected between NGOs and the governmental sector.

Current Situation

The Ministry of Social Security and Labour has been administering the process of deinstitutionalisation for the last few years, mostly by preparing strategic documents and analysing the current situation. However, even with the help of the ministry representatives it has been difficult to calculate the exact number of people with psychosocial or intellectual disabilities in Lithuania currently living in various types of residential social care institutions.

According to the data provided by the Ministry of Social Security and Labour, at the end of 2013 there were 42 social care institutions for people with psychosocial or intellectual disabilities in Lithuania. 6862 people lived there, including 672 minors.

The Ministry of Social Security and Labour itself founded 30 of these institutions, while another 12 institutions were founded by other organisations. 7 of those were founded by municipalities, three were founded by either NGOs or religious communities, and two were founded by private individuals. At the end of 2013, 337 people were living in those 12 institutions (this was the latest data available).

In order to register the reduction in the number of planned places in the care homes during the year 2014, we used the data from 25 institutions, which are directly under the Ministry of Social Security and Labour. According to the two year data gathered, currently there are 6700 individuals living in social care homes in Lithuania. At the end of 2014, 73 beds were eliminated, as compared to 2013.

In most cases, there are fewer residents at institutions founded by municipalities, NGOs, religious communities or individuals. There are fewer than 100 residents in all of the 12 such institutions in Lithuania, while in six of them there are less than 20 residents in each, whereas in the majority of institutions under the Ministry of Social Security and Labour more than 100 residents live in one large institution. The biggest one is social care home of Macikai, which is a home for 465 individuals.

It is not yet clear if institutions which hold under 20 people have to be restructured. Further analysis is needed to assess the aspects of their institutional culture, as well as to provide recommendations for making their practices more effective and professional.

No systematic strategy to reduce the number of beds was observed: whereas in some institutions the number of beds was being reduced, in others this number was being increased. Since this was the first year (14th February 2014 – 14th February 2015) of the plan to transfer from institutional to community-based care, no actual changes have started in practice yet; the efforts were firstly put into planning the deinstitutionalisation process in theory and on the policy level.

In our opinion, the changes of the number of beds in social care institutions is one of the most important aspects which is to be observed in the nearest future. Along with other indicators of development of community-based services, it is important to assess this number every year to monitor the pace of the transitional processes.

The 2014 – 2020 Action Plan for transition from institutional care to family and community-based care for adults with disabilities and children without parental care does not include the assessment of the reduction in beds in residential social care institutions. It is noted in the Action Plan though, that in 2020 the number of adults who have disabilities getting institutional care would decrease by 40 % and 5 social care institutions for adults with disabilities will be reorganised. There are no indicators of the numbers concerning minors who have disabilities in the social care institutions.

NGO „Mental Health Perspectives“ is planning to continue monitoring the ongoing processes within the system of social care as well as in the institutions under other ministries (such as socialization centres, and homes for infants with developmental problems), including the change in the number of existing beds in residential institutions.

Convention on the Rights of Persons with Disabilities. Article 19 - Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to

facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Methodology

The monitoring in the form of visits and interviews took place in the October – December 2014 in the following social care homes: Jasiuliškės, Prūdiškės, Didvyžiai, Strūna, Kėdainiai, Strėvininkai and Aknysta.

Methods of Study

The data was gathered with the help of three questionnaires developed for interviewing the residents of institutions, social workers and administration staff. The questionnaires were developed with the help and advice from the European Network on Independent Living. The data was analysed and reported upon separately for each institution.

Team of Researchers

The visits were administered by representatives of NGOs specialising in mental health and human rights and by a group of independent experts, including individuals who have psychosocial disabilities.

Procedure

In September 2014 guidelines for the monitoring visits were developed. These included general information on the goals of the monitoring study, as well as the course of the study,

methods for gathering data, and subtleties of communication. The Ministry of Social Security and Labour was informed about the goals of the study, the anticipated institutions and a general period of time for visits without giving out the exact dates of visits. However, the institutions were informed about the upcoming visit, the number of experts visiting, and the goals before the visit. Each institution was visited by 4 to 5 experts. Each visit lasted for approximately 4 hours. Data was gathered by using the questionnaires for interviews and observation. From each team of experts one was responsible for drafting the individual institution's report and curating the team during the visits.

Dissemination of Data and Confidentiality

In order to ensure confidentiality, there are no names or personal information of informants given out in the reports. Only summarised information is used in the publication of the study, while the data on separate individual institutions is not published.

Results

Positive Changes in the Social Care System

The Beginning of Deinstitutionalization

Previously, visits to residential social care institutions, the data on related human rights abuses and advocacy for community-based care as well as the need to reform the existing system would not get any support from the governmental institutions. Moreover, refusal to acknowledge the problems would have been the predominant reaction in the past. However, in 2014, the visits were administered with help and approval from the Ministry of Social Security and Labour. The problems were finally acknowledged on the governmental level and the first steps towards solving them were made. Representatives from the Ministry have made several presentations about the need for deinstitutionalization to the employees of residential social care institutions. Furthermore, the ministry also organizes regular discussions of the plans concerning deinstitutionalizations with the employers as well as meetings with the directors of the institutions.

Although scarcely, some of the residents of institutions have also heard about the concept of deinstitutionalization. In most cases, they either learned about reforms from the media or social workers who sometimes describe to them examples from other countries.

Close friends and relatives. The social care institutions are intensifying the cooperation with close friends and relatives of the residents, having their addresses and knowing life circumstances for most of them. A few institutions have been putting efforts into finding the relatives, which in some cases ended up in relatives taking the residents into their own care.

Restoration of legal capacity. There are more and more restoration of legal capacity cases initiated by the institutions themselves. Most institutions hold a few dozens of individuals who are deprived of their legal capacity concerning financial affairs. In some cases the loss of legal capacity took place without the individual's consent, and those were placed in the institutions by the decision of his or her guardian. In such cases of obvious human rights violations, the social workers themselves seek the restoration of the resident's legal capacity as well as getting the overtaken property back to the individual.

Plans to transit people back to community. Although very scarcely, institutions have plans to move back at least 2 or 3 individuals per year back to their community, at the same time reducing the number of beds in the institution.

Qualified personnel. All social workers in the institutions have adequate education and qualifications, what is more, there are further trainings offered, however, these programs rarely include such important issues as the evaluation of individual needs, the social model of disability, living in the community, case management, etc.

The right to independent living in the community

(Un)awareness of the Reform

The hierarchical principles for distribution of information on deinstitutionalization are applied in the social care system as follows: the institution's administration (director and deputy directors) are the most aware of the situation. They are the ones who decide what information, how much of it and when it should be provided to the institution's employees. Institutions' directors not only receive direct information from the Ministry of Social Security and Labour of the Republic of Lithuania, but they are also involved in the reform planning and working groups on the central and

regional levels. Here they are assigned responsibilities for the general planning of the process. However, even those who are most aware lack adequate knowledge about the planned reform. It was noted at the time of the monitoring visits that directors of the institutions do not fully understand the essence of the reform and its comprehensive objectives. And this type of ignorance is usually expressed in a declarative form, such as the following statement: “Here, we will show deinstitutionalization” – a person points to a large extension to one of the social care home buildings. Another example would be a statement like this: “All of our residents are dependent, so where will we deinstitutionalize them to – under the bridge?” On the other hand, some of the staff of the institutions demonstrate exaggerated optimism, which does not reflect the reality: “when there is a need, we will prepare all of our residents for independent living very quickly, but for now we do not see the need” (it is not considered that the residents should be prepared for independent living at the given time).

Since the authority for the information dissemination is with the directors of the institutions, information available to the employees differs significantly in different social care institutions. The administration of one institution state that they talk about the reform with their employees minimally, since there is no specific known details and the administration do not want to frighten the personnel and increase their feelings of insecurity: “when we have any clear and assuring information – we will inform them”. Other institutions inform their employees on a wider scale, but even in these cases, deinstitutionalization is presented as an abstract, a distant idea, and moreover its implementation terms and even potential success is questioned.

The overall feelings of insecurity and uncertain atmosphere is dominating social care institutions. Employees have a lot of unanswered questions, as well as feelings of anxiety about the future of the institution and their ability to secure their jobs. From the employees’ perspective, no practice has been identified of caring for or contributing towards the reform. For example, any additional new tasks or duties are avoided as much as possible, also the employees are reluctant to accelerate any undesirable changes in the existing order. At the time of the interviews on the transition, conducted by the researchers, the employees used such highly emotionally charged terms as “our reduction” and “they are going to divide us”. Some scholar and public figures consider residential care systems to be one of the last bastions of the Soviet times. Paradoxically the workers in the institutions compare the reform to the collapse of the Soviet Union: “it seems to me that this is a similar situation as it was with the Gorbachev and Perestroika: wrong people, wrong time, and wrong money.”

As it was noted before, the residents are informed about the changes last, which directly affects their lives. Moreover, most often they are informed inadequately, for example, residents of one social care institution have been informed that following the reform they will be accommodated in a new building, or vice versa, that they all will be released from the institution. Although the reform should contribute to the improvement of the quality of their lives, residents do not show any enthusiasm or “bottom-up” initiatives. Being used to constant care, they believe that in this respect the “staff will always take care” of them. Such learned helplessness could be handled through independent living skills development and empowerment programmes, nevertheless, as it will be indicated later in this report, so far it has not been applied in practice.



Picture 1. The dissemination direction and scope of the information on reform

The selective and contrasted information, as well as a formed information vacuum overgrows with rumours and hearsays. The reform is perceived as imposed from the top, staff at all levels do not understand their roles and responsibilities within it. This leads to opposition to the reform and willingness to demonstrate that such changes are impossible.

The efforts on the institutional level are focused on maintaining the ‘homeostasis’, i.e. the current situation. While on the ministerial level work is completed through developing strategic documents and making political decisions, the institutions are dominated by uncertainty, inaction and processes adverse to the reform.

High hostility towards deinstitutionalization processes and residential care system reform is observed in the institutions, expectations for the reform to discredit itself are palpable. Although open opposition is not demonstrated, the silent resistance is common. One of the ways through which it is done is ignoring this topic all together, demonstrating no interest and no initiative.

Undeveloped Independent Living Skills of the Residents

The essence of the social care institutions reform corresponds to the main goal of social work, which is to support a person's develop his or her skills and ability to look after oneself. The development of the residents' independent living skills allow to assess staff's ability to perform their professional mission and contribute to the residential social care reform on the micro (individual) level.

Most social workers and their assistants do not perform their main professional function in social care institutions, which is to improve the independent living skills of their clients, and develop their abilities to take care of themselves. Rather on the contrary, not only the efforts are not made but also the depreciated and disrespectful attitudes towards the residents are prevalent: "They do not understand. The disease contributes to it, these people are like vegetables, and it does not matter to them". Such approaches are expressed more intensely in some institutions, while in others it is more latent. In any case, not a single institution demonstrated exceptional efforts or achievements in developing independent living skills of their residents, with the aim of getting them ready for the future life in the community, or at least not suppressing their small individual initiatives.

The strategic plans of some institutions do include the goal to integrate 2-3 residents back to society annually. However, there are no active efforts in place to actually achieve these goals. Quite an accurate assumption based on a long-term observation is that this modest goal would normally be reached through natural change in residents, i.e. some individuals return to their family homes annually and this process is usually initiated by families themselves. The existing gap in the legal framework was highlighted at the time of an informal conversation with the representatives of the Ministry of Social Security and Labour. The order by the Lithuanian Minister of Social Security and Labour (dated 5th April 2006, No. A1-94, Vilnius) regarding The Description of the Procedure of the Establishment of Person's (Family) Need for and Award of Social Services, the Methodology for Establishment of the Need of Old-Age and Adult Persons with Disabilities for Social Care, indicates a very limited opportunity to change the profile of social services for individuals living in social care institutions: 47. *If there is a need to change the type of services for an individual receiving services in a social care institution, the director of the institution has to address the municipality, which had made the decision on the appointment of social services, with the request to change the services.* Such laconically described possibility to ever leave a social care

institution intersects a more detailed scheme on what should be done when the resident passes away. In some of the institutions such scheme is placed in a visible place.

Part of the institutions conduct residents independent living skills assessments, which categorize the residents to “independent”, “partly independent” or “dependent”. Newly arriving individuals are assessed by representatives of their municipality who refer them to social care institutions. Following that further assessments are periodically completed within the institutions, and any changes in residents’ independence level are recorded. Whilst institutions indicate development of residents’ independent living skills as being one of their main goals, at least some sort of progress should be expected. However, despite efforts by social workers as well as institution’s mission which is oriented towards the integration and improvement of the independent living skills, there are no recorded cases of a resident, who had been deemed “partly independent” to be re-assessed as “independent”; neither a person who had been “dependent” to be re-assessed as “partly independent”. According to staff the rather regressive trends are noticed instead, i.e. the “partly independent” individuals lose their independent living skills and become “dependent”. This is particularly common amongst former students of boarding schools, who completed their education, got their diplomas and having had nowhere to go had to come to a social care institution. As staff indicate, in institutions their skills regress.

Self-determination and informed decision making culture is not upheld in institutions either. A number of residents declared being unaware that their independent living skills had been assessed and when the assessment took place. They had not seen their independent living skills assessment results or any other records in their files. On the other hand, in some institutions it was noted that all residents had been encouraged to sign and agree with the assessment results. Those individuals who did not agree with the assessment of “partly independent” reported they were threatened by staff that there would be no place for “independent” ones in an institution, and they would be moved out on to the streets.

According to the indicators listed in the plans and reports of these institutions the development of independent living skills is a process with an end in itself. The anticipated indicators are provided as a percentage, i.e. what part of the residents participate in programmes for independent living skills development, work skills and occupation. The independent living skills development results are not indicated, i.e. how many of the residents become more independent, more prepared to live in the community.

Regressing skills and possession of most basic occupations were also observed at the time of the interviews with residents. Part of these interviews revealed that during the recent couple of years that they had spent in an institution residents have learned how to prepare food, how to obey rules and listened to the social workers, as well as other staff, also how to speak Lithuanian. One of the residents shared the following when asked what she has learned recently: “Dear God. Order, cleanliness, friendliness, sympathy, taking pills... I have come to terms with everything. I write letters, I eat tasty food. I knit”.

It is obvious that such life skills are not sufficient for independent living, instead they are more likely to help residents to function slightly more independently whilst in a social care institution. Integration back into society requires active networking with providers of community-based services, as well as development of the other life skills vital for living in the community, for example, home maintenance, finance management and budgeting, paying bills, logistics related issues, and other life, work and employability skills.

There is an absence of employment even with the mostly motivated residents who express their desire to learn something new, to get education and ask for specific support. Most social workers are guided by a completely unacceptable ‘conveyer-belt’ approach towards organizing their work in social care institutions, stating that: “we work with everyone in the same way, no special conditions will be provided to anyone”.

Social work comes to a complete fiasco even before any implementation of its basic principles is started in social care institutions. Social workers are usually unguided by the social work values, they tend not to respect or appreciate their clients, and struggle to reach any results that are significant to their integrational value.

Improvisations under the Name ‘the Reform of the Social Care System’

The majority of the directors who work in a number of visited institutions are members of inter-ministerial working groups for deinstitutionalization. Regional Development Councils are responsible for the reform processes in the regions. The working groups whose main members are directors of the social care institutions are formed under these Councils in order to develop proposals for the institutional care reform. Paradoxically the main responsibility for planning the social care system reform is with the directors of the residential care institutions who by no means could be regarded as engines of change due to the following two reasons: an obvious conflict of

interest related to the reform and the objective to sustain the administered institution, as well as due to the lack of knowledge and competences in development of community-based services. One regional working group is chaired by a director of a social care institution (a secretary – director of another institution). Another coordinating working group formed under the Regional Development Council consists of 28 persons, 13 of them are municipality representatives, 9 – directors of social care institutions, 5 – heads of children rights protection departments, and one of them is a psychiatrist. Representatives from non-governmental organizations or other experts working in this field are not invited to such working groups where strategical decisions are to be made.

One of the visited institutions was the main developer of the regional vision on services for persons with psychosocial and intellectual disabilities. This explains why the respective vision document as a result does not digress from the former social care model and suggests to continue running the social care institution, reducing the number of residents to 100. Additionally it is proposed to build a new specialized nursing and care home for another 100 individuals where persons with severe psychosocial and intellectual disabilities would live and be treated. According to this scheme the region would have 300 residents in the social care system instead of the current 369 individuals. This indicator is not significant enough, given that the restriction of the access and complete abolishment of huge social care institutions are important in the context of deinstitutionalization. The services proposed at the municipal level are weakly linked to each other, there is a lack of social housing programmes, also the planned independent living homes are too big and in their nature equal to an institution.

More of such improvisations under the name of a ‘reform’ were noted during the visits. For more than a decade one of the institutions has been experimenting by establishing its ‘branches’. Currently there are 5 branches located within a 30 km distance from the central social care institution building. Primarily it was considered to be a progressive idea, however, the established branches were not integrated into the broader network of community-based services and is still an inseparable part of the main social care institution.

A group of 76 individuals in one of the social care institutions live in the former service apartments beyond the institution fence: 5-10 individuals in each apartment and 2 persons sharing each room. All of their occupation activities and meals are organized in the main social care institution premises.

In 2015 one of the institutions is planning to start a supported housing service for 4 of the residents who are assessed as 'independent'. Four women will be moved to the apartment which is located 10 meters from the main social care institution and is currently being renovated for that purpose.

Social care institutions are usually away from any bigger settlements, busy roads, the infrastructure is underdeveloped, and there is a lack of lively community where former social care institution residents could integrate. Community type services developed within the social care institutions adopt the attributes of the institutional culture and follow the medical approach.

Therefore an establishment of the "independent living houses" in the nearby buildings is considered to be more of an expansion of the social care institution and consolidation of the residential care system, rather than a reform. Due to this reason it is not recommended for the institutions to develop community-based services on their own.

Reform processes that take place in the social care institutions are of the facade type, they do not reflect the essence of the reform and rather discredit the idea of deinstitutionalisation than contribute to it. Amateurish and cynical institutions' approach is also reflected by the fact that despite the pressure from national and international organizations to reform the residential care system which violates human rights, Social Care Institutions' Administration Office under the Ministry of Social Security and Labour of the Republic of Lithuania has provided the status of Social work methodological centre to one of the institutions in 2012. Paradoxically, an institution from which residents integrate to live back in the community on the very rare occasions has a certified qualification programme of "Integration of elderly persons with intellectual disabilities into the society through artistic, cultural activities, employment, 40 hours". There are reasonable doubts as to the possession of good practice integrating people with disabilities into society and ability to provide qualitative methodological centre services through this training program.

Gaps at the municipal level

Related gaps at the municipal level determine 2 main obstacles for the deinstitutionalization processes. Firstly, persons with psychosocial or intellectual disabilities are not provided an opportunity to live independently due to the underdeveloped infrastructure of community-based services within the municipalities. Therefore, people are usually referred back to the social care institutions: "Municipalities must take actions, expand the provided services so that they do not

bring up more residents for us; that's where it all starts" (i.e. there currently is no prevention of institutionalization). Secondly, municipalities are not ready to integrate former social care institution residents back into society (i.e. no deinstitutionalization).

Implementing the national (assigned by the Government) function, municipalities are responsible for provision of social care services to people with severe disabilities. Although institutional care is expensive and amounts to around 550-650 euros per month, municipalities choose to refer individuals to the social care homes and pay for their care, instead of initiating and developing community-based services. There are cases of persons having enough independent living skills who are accommodated in social care institutions, for example, 9 individuals from Rokiškis Psychiatric Hospital (which is designated for persons who had committed public offense, and the court recognized their *compos mentis* and appointed them for treatment in strict, enhanced and common monitoring conditions) live in one of the social care institutions. These individuals have quite good independent living skills, however, municipalities fearing for their alleged 'dangerousness' and being unable to offer services corresponding to their complex needs, refer them to social care institutions.

Such an approach allows to avoid investments and save municipal budgets, however the formation of constant demand determines the need for residential care. Moreover, municipalities tend to refer individuals to bigger institutions where the maintenance costs per person are lower. Due to this reason social care institutions aim to retain the current number of beds and show no initiative in demonstrating better achievements in deinstitutionalization than is required by the common stagnation context.

The interviewees particularly highlighted the fact that there are no services developed for independent living in municipalities and therefore they would not be capable to take care of the returning residents of social care institutions. Therefore, according to them, it makes no sense to work with the residents, motivate them, and develop their independent living skills, while at least at this stage this would be a process with the end in itself: a resident who is taught, motivated and prepared for independent living in the community would remain in the institution due to the system related factors.

Cooperation with municipalities has become increasingly more intensive in the past years, however, it remains mostly superficial. According to the interviewees, municipalities currently assess the level of independent living skills of the referred individuals, and the municipality representatives visit institutions before Christmas bringing presents to the residents: "...previously

they would refer people not knowing what kind of institutions those are”. However, the current cooperation might be determined as a one-way process and it by no means addresses the implementation of the deinstitutionalization processes. There are only a few separate cases where social care institutions cooperated with a municipality regarding the returning of their residents back to the community.

The long-term continuity of residential care is also emphasised, when there are no opportunities for young people with disabilities to live independently: “As long as there are such institutions for young people as social care homes for children and adolescents with disabilities, our institutions will not be empty, until then the ‘paternalistic’ residential social care services will have to remain. Municipalities must take action and expand the provided services so that they do not bring up more residents for us; that’s where it all starts.” Not once during the interviews with the employees it was noted that municipalities are not interested in finding other solutions. Referring individuals to social care institutions is the ‘easy’ way: “No person – no problem”. According to the employees, the day care services established in the municipalities do not provide comprehensive services, therefore it would not be a good alternative for residents currently living in social care institutions.

Conclusions

1. The statistical data on adults and children/adolescents with disabilities living in social care institutions is insufficient and only partly available for 2013 and 2014. It also remains unclear if all social care institutions should be reformed, or if the ones which have a smaller amount of residents could remain untransformed. In any way, episodic communication with representatives of the independent living housing services suggests a huge demand to raise employees’ qualification levels, teach them about social model of disability, person-centred approach, individual needs assessment, individual support plans, and results-oriented practices, to change the predominant institutional culture.
2. Comparing the new data with previous monitoring results, a stagnation approach towards the reform and residents rights to live independently, and not ensuring integration into society, can be noted in a number of social care institutions as well as in the residential care system as a whole. There are individuals who leave institutions to live independently,

however, this is not a result of the active staff efforts to integrate them back into society, but rather an outcome of the natural change in the population of residents and other random conditions.

3. The opposing trends are observed – motivated and initiative residents who express their desire to learn, get employed, develop their independent living skills are suppressed and do not get the needed help and support. Staff consider it as exceeding their mandate and usual job functions. Thus they naturally prevent any further opportunities for independent living.
4. There is a lack of clear directives from the Ministry of Social Security and Labour, also municipalities do not develop the network of community-based services. Therefore the atmosphere of uncertainty and passive resistance to changes is predominant inside the institutions. This was also confirmed by the odd situations encountered throughout the monitoring visits when administration representatives admitted to there being no strategy for the reform of their institution, and employees were not informed at all about the planned reforms. At the same time social workers confirm the opposite – that there is such a strategy and weekly discussions on deinstitutionalization take place.
5. Neither administration, nor the social workers take any personal nor institutional responsibility for the changes, the attitude “we could do, but” is predominant. The inaction is blamed on the municipalities which do not develop community-based services, and abusive and manipulative relatives, as well as on the ‘unmotivated’ residents who do not have enough independent living skills developed.
6. The majority of information on the reform of the social care system lies with the institutions’ administration, who communicates directly with the representatives of the Ministry of Social Security and Labour, and who is often involved in the decision making processes at the regional level. Whereas the reform pace is extremely slow, employees do not have the specific tasks assigned that are related to the reform implementation and they are inadequately informed about the deinstitutionalization processes. Residents who are at the very end of the information chain either do not know anything about the changes or know only random interpretations provided mostly by the media.
7. Social care institutions do not have deinstitutionalization plans in place, which could be a starting point for planning the institution’s further work, implementing integration activities with the residents, investing resources and efforts into the development of their

independent living skills. On the contrary, the majority of institutions carry out renovation and reconstruction works that does not address the needed systematic changes and reform that would lead services from the institutional to community-based care.

8. The continuous processes oriented towards consolidation of the residential care system (renovation, improvement of conditions) are taking place in the institutions, instead of being oriented towards development of new community-based services.
9. It is planned to increase the number of residents in the institutions following the renovations, i.e. to conduct activities contrary to the planned reform. Other representatives of the institutions' staff believe, that after the new premises are built or the old ones are renovated the residents will have more comfort: they will alone or 'only' have to share their room with 1 other person, they will have their own bathroom, and this according to the administration will create preconditions for deinstitutionalization. Changes oriented towards realising the reform are the opposite – more of a facade and paperwork level – participation in working groups, discussions in the meetings. Any participation of the employees and residents in related projects, e.g. aiming to teach them a certain craft, is usually episodic and does not lead to continuous employment, nor does it contribute to reaching respective social integration goals.
10. The institutions are aware of the financial threats of de-institutionalization: a declining number of working positions and reduced funding, declining power and general influence, as well as higher work load. Institutions are unable to name even one palpable reason why the planned reform could be useful to them, therefore, there is no motivation to display outstanding achievements in reducing the number of living places or integrating residents into the community. Message formed by the Ministry, civil society and international organizations stating that the system violating human rights has to be reformed, is not accepted as an argument. At the same time it demonstrates the paternalistic approach and opposes the integration efforts by the system representatives. Declarations state that the work is carried out for the good of people, but they do not doubt that the professionals know best what their needs are.
11. The staff of social care institutions understand the main systematic problems, such as stigmatization within society, municipalities' unwillingness to take responsibility for the development of community-based services, misuse of the social care institutions as the final instance or a way to fill in all the gaps. This greatly impedes the functioning, everyday

work and quality of service delivery within institutions. However, social care institutions internalise these problems and do not take the initiative to publicise those, rather the opposite, it contributes to the avoidance and ignorance towards the reform.

Recommendations

1. A separate analysis of the planned living spaces in social care institutions for adults and children/adolescents with disabilities needs to be conducted, as well as an analysis aiming to determine what kind of reform is needed in small social care homes with up to 20 residents.
2. It is necessary to continue an onward independent monitoring of social care institutions for adults and children/adolescents with disabilities, children homes, socialization centres, special education schools, and residences for infants with development delays, aiming to assess the progress, changes and protect human rights of persons with disabilities as well as children's rights.
3. It is especially important to conduct a comprehensive analysis of the preparation for the reform on the regional and municipal levels, to analyse the care appointing processes, assess the services provided for persons with disabilities from the perspective of the social integration back into communities.
4. Clear responsibilities and accountability related to the social care system reform should be determined on the central-regional-municipal-institutional levels, and this should include political decisions (macro level), as well as individual social integration plans and their implementation for each resident (micro level).
5. Employees of the institutions should be informed about the planned reform on all levels. A special focus on providing information should be shifted to the specific roles and responsibilities being assigned to the employees within the process of deinstitutionalization. The dissemination of information should be reinforced by the methodological materials clearly and simply listing principles of the planned reform. As well as indicating what is a negative deinstitutionalization practice, aiming to prevent improper initiatives that ostensibly support the reform. Additionally the perspectives of

employees' future as well as new possibilities to be retrained with the governmental support should be thought over, planned and communicated.

6. It is necessary to define and legally regulate procedures for the social care home residents to leave institutions, determining the personal and institutional responsibilities for preparing the resident for their departure, new services provision in the community and ensuring the continuous person-centred support for independent living.
7. It is a matter of urgency to critically evaluate action plans of the institutions for the following year, identifying and unambiguously rejecting any inadequate developments, constructions, reconstructions or renovations. In some cases this would mean the unilateral suspension of inefficient projects carried out under the pretext of deinstitutionalization (e.g. reconstruction of service apartments, building of new buildings within institutions, etc.).
8. Deinstitutionalization coordinator's position should be established in every social care institution aiming to accelerate the reform activities on the micro level. This should be a adequately trained employee, taking the position of the deputy director whose only function would be to initiate and coordinate the reform activities as well as ensuring the development of the residents' independent living skills. This person should be a contact person on deinstitutionalisation for non-governmental organizations monitoring deinstitutionalization processes, as well as for the Ministry of Social Security and Labour which is responsible for these processes, also for the municipalities which refer residents to social care institutions.
9. Deinstitutionalization process coordinator together with other social workers working at a social care institution, in cooperation with the municipalities referring the residents, should conduct the situation analysis of the individuals waiting in the queue to get into the social care institution, and should provide the proposals regarding the municipal services with the existing or new community-based resources.
10. Community-based services aimed to potentially provide support to former social care institution residents should be developed at the municipalities, as well there should be developed schemes for provision of these services. Various institutions' cooperation algorithms including assessments of individual circumstances of life, personal situations, needs and the use of strengths need to be developed.

11. Representatives of non-governmental organizations and/or their suggested experts should be included into deinstitutionalization working groups operating under the Regional Development Councils.
12. There is a need for expedient, focused and professionally led trainings – practical workshops at the level of local decision makers in municipalities: for directors of institutions, municipality employees, social workers in sub-districts, the main focus being on deinstitutionalization plans. Local decision makers should have opportunities available to them to gain practical knowledge in the institutions based in Western or Northern Europe, and municipalities which had already carried out a similar reform.
13. Regular trainings carried out for institutions' employees is a potential proper resource for the dissemination of information on deinstitutionalization. However, these should not be a formality with the purpose to receive a mandatory certificate. Trainings should be professionally prepared, interactive, adequate for the planned reform, and should provide opportunities to discuss the anxieties of the employees, to develop their capacities, responsibilities, and motivate them to contribute personally to the deinstitutionalization processes.