

## **DEINSTITUTIONALIZATION: CHALLENGES FOR POLICY-MAKERS IN LATVIA**

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**Abstract.** Deinstitutionalization (DI) means moving from institutional to community based services. The DI Action Plan with the EU funding has been issued for 2015-2020. Implementation of it has started through seminars, conferences, meetings, involving professional community of the state social care centres, municipal social services and NGO representatives. However, the mental health issues should be tackled not only among professionals but in strong connection with the whole society. Till now institutional care for persons with mental disorders is predominant and has been strongly supported by the society. Limited visibility of people with mental disorders combined with low tolerance level and poor education creates ground for misinformation through media, creating additional tension and fear. Under conditions of scarce resources, it is crucial that efforts of local authorities, existing mental health institutions and educational establishments for children with special needs are joined to ensure effective integration of people with mental disorders into the society by providing necessary training process, which would foster their social inclusion and integration in the labour market. The article is based on an analysis of legislative acts, existing institutional system, statistics and interviews with social workers, experts and representatives of NGO's and local governments.

**Key words:** deinstitutionalization, mental health disorders, community based services, public awareness.

**JEL code:** H75

### **Introduction**

The World Health Organization (WHO) in 2002 did an assessment on Mental Health System in Latvia (published in 2006) and concluded: "On the whole mental hospitals still are predominant in the mental health system of Latvia and there are no community residential facilities available in the country. The consumer associations and the family associations are small in size (respectively 2 users/consumers and 15 family members). The government did not provide economic support for these associations. There is no coordinating body to oversee public education and awareness campaigns on mental health and mental disorders. Agencies, institutions or mental health services have not promoted educational campaigns in the last five years" (World Health Organization, 2006).

Concluding remark of this report was that "from a larger point of view, the mental health issues should be tackled not only among professionals but in strong connection with the whole society. Downsizing the mental hospitals, promoting campaigns against stigma, and increasing the participation of users and families implies not only technical choices, but also a large participation of the stakeholders and of

large sectors of the society to these choices" (World Health Organization, 2006). Authors consider that changing the attitude of society towards persons with mental disorders and the dominating opinion that institutionalization is a better and more secure solution for those persons still remains among the largest challenges of the deinstitutionalization (DI) policy. It is a serious challenge – to accept something different, unusual and hardly predictable in our daily life. It also partly explains the strong bias towards refugees, despite of rather small figures. The numbers of persons that should leave institutions during the DI process is rather similar (700) and additional 1400 persons should be prevented of being institutionalized. There are ongoing public debates concerning refugee integration and no public discussions concerning the DI process. However, the DI process affects not only persons with mental disorders and their families, but also authorities on local, regional and national level, social workers, primary health doctors, psychiatrists. It requires high level of coordination and cooperation among many different institutions: the Ministry of Health, the Ministry of Education and Science, the Ministry of Welfare, the Ministry

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of Justice, the Ministry of Regional Development and Environment, the Ombudsman and various NGO's.

Currently a large scale European Funded project to facilitate the DI process in Latvia has begun and it is reasonable to evaluate how the WHO recommendations concerning public education and raising of public awareness have been taken into account in the DI policy implementation.

The article is based on an analysis of the existing legislative framework, the institutional system, available statistics, interviews with social workers, experts and representatives of NGO's, state and local government authorities. The DI process is in its initial stage, thereby early monitoring and assessment is important for policy quality.

### **1. World Experience of Deinstitutionalization**

Deinstitutionalization is a long-term trend wherein fewer people reside as patients in mental hospitals and fewer mental health treatments are delivered in public hospitals. This trend is directly due to the process of closing public hospitals and the ensuing transfers of patients to community-based services in the late twentieth century (Encyclopaedia of Mental Disorders, 2015). The DI process implies independent living in the community for clients of the state social care institutions and development of community based services. DI means radical shift in disability policy from passive medical approach to human rights and inclusion, it is person oriented, shifting from disability to functionality. In general, DI is valued as a more humanistic approach and a positive alternative to the institutional care. However, an important shortcoming of DI is the fact that people, who have been long-term clients in social care institutions, find it difficult to adapt themselves to independent life. As evidenced by the fact that 30-50 % of homeless people are

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-100 persons with mental disorders (Encyclopaedia of Mental Disorders, 2015).

The USA implemented a project, during which chronically mentally ill people were trained and involved in labour relations. The project started in 1970 and was still effective in 1990. Special social care employees were trained to be able to cooperate with unemployed persons, to motivate them, to help with daily chores, to meet employers to persuade them to train and employ mentally ill persons. The project was successful and viable; monthly on average 40-50 people were trained for simple jobs (Forte, 1991).

A research in Australia was carried out to study the impact of DI on clients who had resided in regional municipal alternative social care institutions from 1996 until 2007. Their quality of life had improved due to a friendly living environment; there were fewer cases of relapses when they were sent back to a psychiatric care institution. At the same time, it was concluded that further improvement of living conditions for the target group should be achieved by putting more emphasis on their social inclusion and integration into the labour market. It was recommended to pay more attention to clients who were not accepted in the municipal alternative care institutions, as for the person it meant a higher risk of becoming homeless or drug addict. Furthermore, increased attention should be paid to people who did not qualify for municipal care facilities, but were actually mentally ill, as it would reduce the risks of disease relapses and prevent disability (Hamden, Netwon, Cauley-Elsom, Cross, 2011).

In the Scandinavian countries, the DI process started in the 1990-ies. States allocated resources to ensure successful implementation of this policy via specialist training, provision of assistants, education of the community, starting from pre-school institutions, creation of work places for the target groups etc. Mentally disabled young people could acquire job skills in special workshops. These children acquire

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education together with other children in general schools, they only have special supportive training programmes and methods. Children study together in pre-school institutions as well. Lately in Norway, a new trend has appeared to abandon individual care and to return to group homes or group apartments, as it is becoming too expensive (Silina, 2015). In 2010 a research was carried out in Norway on living conditions and quality of life for individuals with mental disorders. It was based on surveys from 1989, 1994, 2001 and 2010. The research was done 20 years after the introduction of a nationwide social care reform in Norway. The target groups were persons with mental disorders, aged 20-67. The data of the research were compared with the data obtained before the reform in 1989. In the period of 2001-2010 people's self-determination possibilities had slightly increased, however, the organizational shortcomings had doubled. The reform was successful in the introductory stage. After 1994 there was certain stability in alternative services, but gradually various organizational shortcomings appeared, and in 2010 the situation became critical. The municipalities had returned to large community homes that were twice as big as recommended by the guidelines recommended. Daily activities were quite opposite to the idea of normalization. Possibility to plan their daily life was minimal. It was a great challenge for Norway to return to the

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-101 original path of the reform, and to prevent the identified negative trends (Soderstro, Tossebro, 2011). Furthermore, it should be outlined, that in 2003 in Sweden, where the DI process begun in 1995, intensive debates were provoked by the increasing number of criminal offences done by persons with mental disorders, therefore causing severe doubts about the successfulness of the DI reform.

Many researchers underlines, that if dominant view in society is in favour of institutional care, it hinders introduction of alternative social care of person with mental disorder. Especially strong such attitude has been noticed in post-socialist countries (Dagg, Morrow, Pederson, 2008).

## 2. Overview of the development of the DI process in Latvia

Latvia already has some DI experience (Table 1): group houses, day care centres for persons with mental disabilities, half-way houses. Every year clients move from institutions to community-based services. In 2014, there were 82 day care centres, of which 23 in cities and 59 in municipalities. Recently day care centres for people with dementia are becoming more popular. Several municipalities have developed new services based on ICT, i.e. security buttons. Also mobile care teams are used to provide more differentiated services. However, coverage of these services is low and territorially uneven.

Table 1

### Community based care in Latvia in 2013 - 2014

	The number of clients	The number of institutions	The number of municipalities
Group houses	206 / 273	14/13	9/9 (8%)
Day care centres for person with mental disabilities	782 /811	26 / 29	22/23 (19%)

Source: Jasjko, 2015

Nevertheless, institutional care in Latvia has always been the dominant type of care for people with mental disorders, already since the interwar period. Its content had only slightly changed during the years of soviet rule. People with

mental disorders or physical defects and orphans staying at specialized institutions were perceived as a normal phenomenon. In the first half of the 1990s, centres for mentally disabled were closed institutions with a hospital regime, where

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inmates lived practically isolated from the surrounding environment. Reforms of social services in Latvia started in the mid-1990s when the Law on Social Assistance entered into force in 1996.

In 2002, there still were no alternative community based social care services for mentally disabled persons in Latvia (World Health Organization, 2006). In 2006, there were 36 social care centres for adults with severe mental disorders able to accommodate 10118 persons. Although, the number of clients at the social care institutions increases year by year; yet demand for this type of service has not been fully met. The Ministry of Welfare explains that it is due to the fact that the decision-making lies upon the local government, not foreseeing any financial obligations for its decision. As a result, persons with various degrees of disturbances live at social care centres, including persons who might have lived outside institutions if adequate community based services would be provided (The Ministry of Welfare, 2006).

On January 15, 2005 Latvia joined the WHO Mental Health Declaration for Europe and introduced the Action plan of the Mental Health Declaration 2005-2010, therefore agreeing to further on develop mental health policy in which institutionalization would be allowed only in cases when important personal or societal security would be endangered. Although also previously several policy planning documents indicated the need for a gradual move towards DI, first group houses in Latvia were established only in 2005 and first halfway houses only in 2007. Furthermore it should be outlined that at that time there were coordinating problems between the Ministry of Health and the Ministry of Welfare. As a clear evidence of that were two content-wise similar policy documents (Guidelines for improvement of public mental health 2009-2014 by the Ministry of Health and Programme for development of social care and social rehabilitation services for people with mental

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-102 disorders 2009-2013 by the Ministry of Welfare) issued by the two ministries tackling the same issues, yet highlighting different desirable outputs and outcomes (Stavausis, 2011).

As for the moment, DI tasks in Latvia are set by the "Guidelines on Development of Social Services 2014-2020". They envisage assessment of individual needs of clients in social care institutions and development of infrastructure, and services according to individual needs in municipalities, closing of state social care institutions and training of professionals for provision of new services. The guidelines foresee activities to prevent further institutionalization if there is a possibility to receive alternative services (Cabinet Regulation No 589, 04.12.2013). Furthermore, a methodology was elaborated for client grouping and assessment and in 2013 primary assessment of functional disabilities was carried out. Persons with relatively mild health and behavioural disorders were put in categories 1 and 2, while with categories 3 and 4 people who need serious social and health care were identified. It was concluded that 43% of clients could be assigned in group 1 or 2 (The Ministry of Welfare, 2014). It means that at least part of them should withdraw from institutional care.

Currently, the DI process in Latvia focuses on the society's most vulnerable groups of people. There are three DI target groups in the planning period 2014-2020: 1) adults with mental disabilities, living in municipality or state social care institution; 2) children in out-of-familial care, up to 18 years old, living in child care institutions; 3) children with disabilities, living in families.

The Government of Latvia has approved the Operational Program "Growth and Employment" objective of the 9.2.2 "Increase quality alternative to institutional care of social services at home and in a family environment closer to services for persons with disabilities and children" on June 16, 2015. This programme defines the

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use of available funding (EUR 47 209 260), requirements to EU Project applicants and cooperation partners and conditions of implementation until 2023 etc. Planning regions will execute the funding allocation (Cabinet Regulations No 313, 01.07.2015.).

On July 15, 2015 the Ministry for Welfare issued the Directions on Implementation of the DI Action Plan 2015-2020. The Action Plan explains DI as a service system that provides person who has limited ability to take care of him or her, the necessary support to be able to live at home or in a family environment. DI is focused on promotion of independent living, self-determination, participation and inclusion opportunities to people with disabilities. The plan includes implementation schedule of the DI measures, indicating responsibilities of all parties and time allocated for each activity (The Ministry of Welfare, 2015).

Introduction of DI requires essential behaviour change for target group persons. The person needs assistance after leaving the institutional care centre where everything was provided, and now they start living an independent life where they will obtain freedom, but they will also face other restrictions and duties. It is even more difficult for long-term clients of State Social Care Centres (SSCC). Recent survey of halfway home residents showed that most of the clients wish to go on living in a halfway home (88%), while 38% said they would not like to live anywhere else but 7% expressed a wish to return to a social care institution (Mikelsone-Slava, 2015). Due to the low demand for the DI services from the target group the number of halfway houses in 2015 has remained unchanged. Furthermore, there are no waiting queues for these services (Silina, 2015).

The DI guidelines indicate that the institutional culture and its negative consequences are not automatically eliminated with dismantling of large long-term care centres, institutional culture maybe transferred to community-based services. Therefore, frequent

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-103 and regular client satisfaction evaluations are necessary in order to monitor services and adapt them in case of necessity. In this regard, the key factor is training of the personnel according to the principles of the UN Convention on the Rights of Persons with Disabilities (EASPD, 2013). It is the right time to start evaluating individual needs and resources and join efforts of policy makers, local authorities, service providers, institutions, NGOs and the society. Involvement of professionals and representatives of target groups has been activated during 2014-2015 extensively through seminars, conferences, meetings and discussions on local, regional and national level organized by the Ministry of Welfare. However, very little has been done to introduce and involve the general society in the decision making and policy implementation process, therefore it is reasonable to ask, what role and at what level should (if at all) they be involved in the overall DI process. As interviews with experts have explicitly outlined, there is no consensus on this issue among professionals.

### 3. Discussion

"I would evaluate the available information as poor, very little has been done to involve specialists and the society in the DI process," acknowledges Gunta Anca, the chairperson of the Latvian Umbrella Body for Disability Organisations "Sustento". She believes there is a great need for wide-spread informative campaigns to introduce locals with the service receivers, so they would understand that "they" are just like "us" and there is no need to be afraid. Also the director of a group house Tamara Vahlina is disappointed with the way how the DI implementation process has been carried out: "It seems that this information is a secret. We were asked by the Ministry of Welfare to give our opinion during the drafting process; however we know nothing about its implementation. And it is not the first time the Ministry acts in this manner. As we are members of the European Association,

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frequently we receive information about the situation in Latvia from them faster than from Latvia itself." The director of a SSCC Modris Karselis admits that information is given by theoreticians and acting professionals and it more resembles a directive. However, he thinks that it should be aimed at explaining the situation and must involve broader society, including and respecting local governments, which, after all, make the foundation of the state.

Different opinion is given by Maris Gravis, chairman of the Board of the Society "Riga City Caring for Kids with Special Needs", project development group member for DI introduction in Latvia, who thinks that a broad scale information campaign about DI does not correspond with the interests of customers and policy makers. He believes that the DI process will not change the structure of the society; hence, people who do not know about this issue will not be informed further ahead as well. It tackles very particular group of people and only their private life. Before anything concrete has been initiated within the DI process, it would be unreasonable to involve broader society as it could escalate unwanted negative emotions. Only when it will be clear what actions will be implemented people living in the vicinity should be informed on what and how is planned and will be done. Santa Ravica, the Deputy Head of Burtnieki County Social Care Service, is confident, that within the DI process "the greatest challenge for the society will be to accept that their neighbours are people with mental disorders, to accept the differences in their daily life, to help, but not to condemn or gossip".

Such reserved approach to broader scale information campaign can be understandable and some researchers have pointed out to problems it may lead to. Dagg, Morrow and Pederson outline that "how society cares for people with mental illness reflects its social and economic tensions and highlights that care occurs, not only in a

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-104 medical, but also a political context. Thus, there have consistently been ebbs and flows regarding society's tolerance for deinstitutionalization and the visibility of people with mental illnesses. Calls to re-institutionalize people are rarely based on research evidence and instead garner support through editorials and sensationalized media reports of people with mental illnesses as violence and unpredictable" (Dagg, Morrow, Pederson, 2008).

However, other interviewed experts have explicitly stressed the necessity for a broader involvement of the society, as it would facilitate debate on the speed of the reform process and it could lead to better decisions on how to use the available resources to improve the service quality and make the adaptation process easier. For example, little discussions have been initiated, whether the reform process should be gradual or radical. Interviewed experts lean towards a more gradual reform approach to avoid destruction of effectively functioning good things. M. Karselis suggests: "Is it worth destroying one infrastructure to make a new one? Why not build a multifunctional service on the basis of the existing one with financing from the state, municipalities and private persons, who can provide long-term care and leisure activities? By joining all resources, the service quality would improve. The process should be gradual to prepare a maximum number of clients for independent life in the society but not by any price push unprepared people onto the streets."

Another issue mentioned by many experts was the restrictive legislation which does not allow SSCC clients to do paid work, as they are in a full state care, thus it is impossible to train real job skills for life outside the institution. Clients are allowed to work in workrooms and fulfil self-catering services, but they cannot do jobs for which paid staff members are legally provided, like caretakers, kitchen workers, janitors etc. This prevents them from understanding the real situation on the labour market. Local

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governments alone are not capable to ensure employability; therefore all ministries should be involved in this process. The formula is simple: without appropriate work places, the reform will not bring the desired outcomes. Already existing half-way houses and group houses operate idling. M. Karselis offers a practical solution, approved abroad, how to prepare the SSCC clients for life in the society: Legislation should provide a basis for practical employment where the client could learn work skills working together with a staff member, e.g. by cleaning premises. In current situation the Ombudsman may arrive and declare that a client is employed illegally. A client who is able to do many things should be allowed to work, and then things will happen. Law should guarantee community-based care, so that entrepreneurs might be competitive and feel the state support.

Almost all interviewed people also point out the confusing mechanism of the DI financing as a significant risk factor. Gunta Anca says: "I am afraid that a lot of money will be provided. But shall we be competent enough to use it wisely, knowing that it is European money? When the project is over, there will be no money." Many sub-activities of the community based services (95 projects in total) were carried out in 2010-2013, receiving support worth EUR 11.8 million. In total 18,464 persons benefited from these projects. Within these projects 131 provider of social services were involved. Despite impressive figures this experience was not evaluated positively. Maris Gravis claims that "the previous negative experience with management of European funds has led to negative stress. Support to clients was insufficient regarding the half-way and group houses in municipalities; as a result, people were left in worse conditions than they were before. This created an apprehension that after the DI most of the clients would be homeless".

Services, which were initiated with the financial support of the European Funds, were

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-105 closed down because of the lack of available resources. This is particularly true with day care centres in smaller local governments. As a result in future it leads to distrust and suspicion. M. Gravis explains that "changes would require large cross-financing mechanisms, amendments in legislation and political decisions... We have pointed out in our plan that the Ministry of Welfare should strictly keep to the idea that 'money follows the client'. We have listed it as a mandatory issue which should be developed by the beginning of 2016 when the municipalities will have a clear vision of what will come after the project termination. One scenario could foresee continuous state financing, another – that the government and the Latvian Association of Local and Regional Governments conclude an agreement of redistribution of personal income tax, provided that municipalities continue to fund the service. Definitely the existing system must be changed". Available financing is, thus, another important reason outlining the need for a broader society involvement and debate on how the available resources should be spent.

### **Conclusions, proposals, recommendations**

- 1) Society in Latvia still prefers traditional institutional care for persons with mental disorders, caused by limited information and lack of any awareness campaigns on mental health, mental disorders and the DI process. Limited visibility of people with mental disorders combined with low tolerance level and poor education creates ground for misinformation through media, creating additional tension and fear.
- 2) Previous unsuccessful experience has approved that the DI process lacks clear long-term financial perspective and planning, when ongoing projects had to be cancelled due to the lack of available resources, especially affecting small and poor municipalities.
- 3) The DI process requires constant and ongoing cooperation and coordination among

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all stakeholders (the Ministry of Welfare, the Ministry of Health, the Ministry of Education and Science, the Ministry of Justice, local governments, social workers, NGO's), not only in the policy planning process but also in the policy implementation phase.

4) On conditions of scarce resources, it is crucial that efforts of local authorities, existing mental health institutions and educational establishments for children with special needs are joined to ensure effective integration of people with mental health issues into the society by providing necessary training process, which would foster their social inclusion and integration in the labour market. Pre-emptive actions as such not only would make the transition from institutions to community based services easier, but also

Jelgava, LLU ESAF, 21-22 April 2016, pp. 99-106 would prevent institutionalization of 1400 people who, according to the programme, have mild mental disorders and are capable of living independent lives within the community. 5) The target group of DI is among the most vulnerable in society, which cannot protect itself. To ascertain the real situation, it is necessary to carry out regular monitoring and independent research to explore the target group's satisfaction with the living conditions, opportunities to be employed in line with their needs and abilities. Once the DI process is started, the possibility to return to institution will be limited in case clients cannot adapt to life outside the institution. It is difficult to assess the independent life skills of clients while they are institutionalized.

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