COMPARATIVE ANALYSIS OF THE IMPLEMENTATION OF ARTICLE 19 OF THE UNITED NATION CONVENTION OF THE RIGHTS OF PEOPLE WITH DISABILITIES IN EIGHT EUROPEAN COUNTRIES

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ABSTRACT

The transition from institutional to community care for vulnerable people has been shaping the welfare system in Europe over the last decades. For the period of 2014-20, deinstitutionalisation became one of the highlighted priorities of the European Commission in order to promote reforms in disability and mental health care in the convergence regions, too.

Between 2007 and 2013, Estonia as many other Eastern European countries implemented the first wave of deinstitutionalisation, and during the new EU budget period a second wave will be carried out in order to continue and hopefully complete the transition. In this study, we try to give an overview of the experiences of different European countries, highlighting good practices and possible pitfalls.

Keywords: deinstitutionalisation, community-based services, disability care, mental health, European Union

METHODOLOGY

Our study is based on an analysis of relevant policy papers that have been extended by interviews with key experts of the given countries. Within the framework of this study, we use the United Nations Convention on the Rights of Persons with Disabilities as a legal reference for the terminology and definition of deinstitutionalisation and community living, while we consider the Guidelines of the European Expert Group¹ as a policy reference.

This study has been conducted at the request of the Estonian Ministry of Social Affairs.

We included 8 European countries in our analysis:

- Czech Republic
- Estonian
- Slovakia
- Hungary
- Romania
- the Netherlands
- United Kingdom

¹ Common European Guidelines on the Transition from Institutional to Community-Based Care http://deinstitutionalisationguide.eu/ (last download: 26th of September 2015)

Sweden

The selected Eastern European countries can provide us with an opportunity to explore their progress and difficulties with the implementation of deinstitutionalisation, while the selected Western European countries can be analysed from the perspective of the latest developments in community care. Countries were selected based on the preferences of the Estonian Ministry of Social Affairs.

In our research, we relied on the monitoring system of the UN Convention. The Convention ordered to set up a systematic monitoring system that is run by the Committee on the Rights of Persons with Disabilities. The Committee is a body of <u>18</u> independent experts², which monitors the implementation of the Convention on the Rights of Persons with Disabilities.

The monitoring process is a well-documented communication between the state parties and the Committee. Each country submits an Initial Report, where they summarise all their efforts to implement the Convention. The Committee creates a List of Issues as a reaction to this report and each country has an opportunity to reply to the list of issues. An official face-to-face hearing is also organised, and after that the Committee publishes its Concluding Observations. This monitoring system provides us with an excellent and detailed overview on the implementation of the UNCRPD.

In four of the selected countries (Sweden, Czech Republic, Hungary and Slovakia) and in the EU, the first round of the whole monitoring process has already been finished, while in two countries (the Netherlands, Romania) the process hasn't started yet.

Table 1.: Monitoring the process of the Committee on the Rights of Persons with Disabilities

Country/Document	Initial Report	List of Issues	Replies to the list of Issues	Concluding Observations
United Kingdom	Submitted	Submitted	Submitted	-
Sweden	Submitted	Submitted	Submitted	Published
The Netherlands	-	-	-	-
Czech Republic	Submitted	Submitted	Submitted	Published
Hungary	Submitted	Submitted	Submitted	Published
Slovakia	Submitted	Submitted	Submitted	Published
Romania	-	-	-	-
Estonia	Submitted	-	-	-
EU	Submitted	Submitted	Submitted	Published

In our analysis, we paid particular attention to the implementation of Article 19, which concentrates on the right to live independently and to be included in the community.

Beside the officially submitted and published documents of the monitoring process, in many countries we had an opportunity to analyse shadow reports and independent studies on the implementation of deinstitutionalisation.

Furthermore, we have conducted interviews with key experts in each country in order to extend the information we received during our desk research and to clarify our questions. The interviews were conducted over Skype or via e-mail using the method of semi-structured interviews.

Interviewed key experts:

• **Czech Republic:** Jan Pfeiffer – psychiatrist, founder of many community-based initiatives in the Czech Republic, former chair of the European Expert Group.

- Slovakia: Maria Machajdíková researcher, SOCIA Foundation
- Hungary: István Sziklai researcher, ELTE University Faculty of Social Sciences
- **Romania:** Elena Tudose researcher, program director at Institute of Public Policy in Bucharest.
- The Netherlands: Dr Els Overkamp senior researcher, Research Centre for Social Innovation
- United Kingdom: Dr Nick Hervey expert in the history of the UK mental health system, and former senior manager in mental health and social care
- **Sweden**: Lars-Göran Jansson director, Göteborgsregionens Kommunalförbund, Vice-chair of European Social Network

Definitions of deinstitutionalisation and community living

While all the reference documents are emphasising the importance of a clear commitment toward deinstitutionalisation and community living, there is no universal definition for these terms.

Article 19 of the UNCRPD approaches the issue of independent living and community inclusion from the perspective or equal rights. It doesn't mention deinstitutionalisation as a relevant policy to ensure these equal rights, but puts an emphasis on the desired outcome of any policy measures that have to aim at giving the opportunity of having a free choice of place of residence and access to community-based housing or residential services.

"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."³

The Guideline of the European Expert Group⁴ describes in detail the transition from institutional to community-based care. To create a common understanding, they defined institutions as the following:

"There are different understandings of what constitutes 'an institution' or 'institutional care' depending on the country's legal and cultural framework. For this reason, the Guidelines use the same approach as in the Ad Hoc Report. Rather than defining an institution by size, i.e. the number of residents, the Ad Hoc Report referred to 'institutional culture'. Thus, we can consider 'an institution' as any residential care where:

• residents are isolated from the broader community and/or compelled to live together;

³ United Nation Convention on the Rights of Persons with Disabilities Article 19 http://www.un.org/disabilities/default.asp?id=279 (last download: 29th of August 2017)

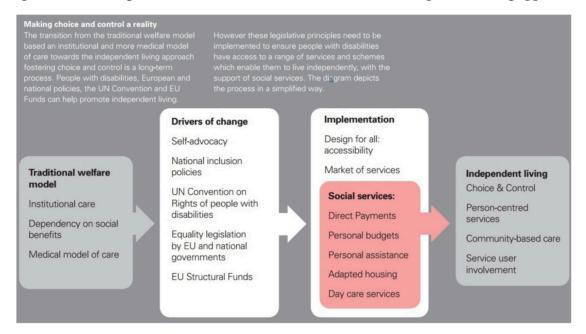
⁴ Common European Guidelines on the Transition from Institutional to Community-Based Care http://deinstitutionalisationguide.gu/ (last download: 29th of August 2017)

- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individualised needs."5

The European Social Network (ESN), as a member of European Expert Group on Transition from Institutional to Community Care, has published a report in order to outline the first steps in deinstitutionalisation and identifying key elements for good community care. The ESN also published a report on how social services in different European countries are promoting choice and control alongside people with disabilities.

In the following figure, we can see a summary of the optimal transition from a traditional welfare model based on an institutional and more medical model of care towards the independent living approach in the community.

Figure 1. The process of shifting from traditional welfare model towards an independent living approach



Source: European Social Network

Analysing the communication between the UN Monitoring Committee and the selected state parties, we can have an overview of how different stakeholders interpreted the given legal frameworks and policy guides.

Due to the fact that there is no strict definition for institutions, institutional care and community care, different state parties identified their existing situation very differently.

In Sweden, the basic objective of the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)⁸ is to enable this group of individuals to live as others do. The social welfare boards of local municipalities are obliged to ensure that persons who encounter difficulties in their everyday lives are enabled to participate in the life of the community and to live as others do.

⁵ Common European Guidelines on the Transition from Institutional to Community-Based Care p.25. http://deinstitutionalisationguide.eu/ (last download: 29th of August 2017)

⁶ Developing Community Care – Report of European Social Network. 2011. Brighton UK. http://www.esn-eu.org/developing-community-care/index.html (last download: 29th of August 2017)

⁷ Independent living: making choice and control a reality – Report of European Social Network. 2011. Brighton UK.

http://www.independentliving.org/docs3/englss.html (last download 29th of August 2017)

In the UK, the right of independent living has a crucial importance. "The UK's approach to independent living goes well beyond the right as described in Article 19 and encompasses increasing choice and control, removing barriers and inclusion in the community. This approach underpins the rights set out in many of the other articles of the Convention. Independent living means having choice and control over assistance and/or equipment needed to go about daily life, and having equal access to housing, transport and mobility, health, employment and education and training needs."

In Slovakia, the government emphasises that the provision of social services in the community or in out-patient facilities has priority over the provision of social services in an institution on a residential basis.¹⁰

Romania didn't submit its initial report to the UN Committee yet, but in a report¹¹ of the European Coalition for Independent Living (ECCL) we could explore that the Romanian Institute for Public Policy considers the lack of a clear objective in the national strategy for deinstitutionalisation to be a fundamental problem. Although the National Strategy for People with Disabilities refers to the development of community-based services and includes social integration as an objective, it does not make explicit requirements to replace existing residential institutions with community-based services.

In the Hungarian initial report, we can find that "If 24-hour care is needed for supporting independent living the traditional forms of institutional social care – caring-nursing homes, rehabilitation institutions provide solution in addition to the homes operated for such persons."¹²

In the Czech Republic, the initial report of the government also considered traditional large institutions (homes for persons with disabilities) as services related to Article 19 of the UNCRPD.¹³

Although the Constitution of the Republic of Estonia does not expressly state that people have the right to live in a community, it is implied in the principle of human dignity provided for in the Constitution. The Constitution also provides that everyone has the right to choose freely where to reside. The main problems with the provision of social services to disabled people are related to the availability and quality of the services, as those vary across local governments because different local governments have different administrative capabilities due to their territory, revenues, population size, etc. A person should enter the 24-hour care service only as a last resort, when all other measures to support the person have failed and the person's coping cannot be ensured by other services.¹⁴

As we can see, while in Sweden and in the UK community participation is emphasised, in five Eastern European countries institutions are still considered a relevant part of the service system.

In a study on mental health, European researchers were exploring the proportion of mental health services to compare the weight of institutions and hospital care with service capacities in community care. The authors revealed that in all the new member states (and in many Western European countries, too) institutional care is still considered the mainstream of the welfare services, while community-based services outnumber institutional care only in countries where the process of deinstitutionalisation has already been implemented over the previous decades.¹⁵ (see Map 1.) Similar results can also be seen in disability care.

The lack of a clear (operational) definition for community living and institutional care led to a wide variety of understand-

⁹ Initial Report of the United Kingdom of Great Britain and Northern Ireland to the UN Committee on the Rights of Persons with Disabilities. November 2011.

¹⁰ Initial Report of Slovakia to the UN Committee on the Rights of Persons with Disabilities. January 2012

¹¹ Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living, European Network on Independent Living – European Coalition for Community Living, December 2013 http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf (last download 29th of August 2017)

¹² Initial Report of Hungary to the UN Committee on the Rights of Persons with Disabilities. October 2010

¹³ Initial Report of the Czech Republic to the UN Committee on the Rights of Persons with Disabilities. November 2011

¹⁴ Initial Report of Estonia to the UN Committee on the Rights of Persons with Disabilities. November 2015.

¹⁵ Mapping Exclusion. Institutional and community-based services in the mental health field in Europe. Mental Health Europe. Brussels 2012 http://tasz.hu/files/tasz/imce/mapping exclusion - final report with cover.pdf (last download: 29th of August 2017)

ing and interpretation of Article 19, and the first wave of deinstitutionalisation has been implemented based on these varying concepts.

Map 1. Long-term care in institutions vs. community care in the field of mental health care in Europe.



Source: Mental Health Europe

The first wave of deinstitutionalisation

The importance of the transition from institutional to community care was not obvious, even in countries where this transition was considered successful so far.

In Sweden, the first wave of deinstitutionalisation turned out to be a failure. The political decision on closing down institutions was made in 1993, and the process of deinstitutionalisation lasted for 7 years.

Former institutions became hotels or conference centres, while new housing opportunities were provided by local municipalities. The relatively fast implementation might have occurred since there was an obvious commitment on behalf of all stakeholders toward deinstitutionalisation, and they could rely on the experiences of other countries like Italy or the United Kingdom.

However, the first attempt of deinstitutionalisation ended up as a failure because the first community housing instances were rather a group of group homes, and segregated "disability" blocks instead of real integration. Very soon it became clear that the situation of residents hadn't really changed in these settings, the culture of large institutions and also the segregation from real communities were transformed to the new services.

A second turn of deinstitutionalisation was implemented in Sweden, taking into consideration the principle of real community integration.¹⁶

Studies performed by Ravelli (2006) focused on how Dutch mental health care specifically developed toward deinstitutionalisation from 1993 to 2004.¹⁷ In this period, almost all general psychiatric hospitals were involved in mergers with at least one regional institution providing ambulatory mental health care (regional ambulatory mental health care institutes). In 2015, there were 30 integrated mental health care institutions and 41 specialised agencies, including 20 organisations for community living.

The main lines of the change process in the period until 2005 focused on building new facilities, streamlining referrals and setting up care programmes. "Care circuits" (networks) were formed, which are organisational units where similar treatment programmes or care facilities for a particular target group are combined.

De-hospitalisation and decentralisation were the key concepts for the above processes. In practice, these concepts were translated into the replacement of clinical facilities by part-time clinical treatment or completely extramuralised forms of treatment, such as home care, supported housing and Assertive Community Treatment teams. During the last decade, most of the regions have created FACT teams, which provide both intensive care and psychosocial support to persons with psychiatric disabilities living in a community or in supported housing facilities. The 'F' stands for 'function' or 'flexible', meaning that the care can be flexible in terms intensity, according to the needs of the client.

The number of places in institutions for the care of people with intellectual disabilities in the Netherlands did not decrease over the years. Instead, deinstitutionalisation took place in the form of moving places to all kinds of settings in the community.¹⁸

Supporting persons in the community with regard to self-care and participation is the main focus of the new Social Support Act, which entered into force on 1 January 2015. As a result of this act, local municipalities became responsible for these services. Most of the local authorities created integrated multidisciplinary social teams to provide an array of services to the whole population, so not only persons with mental health problems, but also people with a learning disability and the elderly.

In the new system, only treatment and 24-hour care remain centralised through the budgets of the medical insurance companies. All the other forms of care and support have become the responsibility of the municipalities. The money has been transferred from the state budget to the municipal budget, but with a budget cut of 25%.

¹⁶ Source of the information is the presentation of Lars-Göran Jansson on the Seminar on deinstitutionalisation of the European Social Network in Warsaw 2009 and also on the interview we conducted with him within the framework of this research.

¹⁷ Taken from: Ravelli, D.P. (2006). Deinstitutionalisation of mental health care in the Netherlands: towards an integrative approach. *Int J Integr Care*. 2006 Jan-Mar; 6: e04. Published online 15 March 2006. Retrieved: October 14, 2015. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1480375/

¹⁸ Schuurman, M. (2015), Naar de samenleving. De transformatie van de inrichtingszorg voor mensen met verstandelijke beperkingen in Nederland, tussen 1989 en 2014. *NTZ 1*-2014, 10-34.

The United Kingdom has a long tradition of deinstitutionalisation and developing community-based services¹⁹

In 1971, a Government paper on 'Hospital Services for the Mentally Ill'²⁰ proposed the complete abolition of the mental hospital system. There was a shift towards the provision of other community-based services for people with mental illnesses, such as supported housing, day services and community-based mental health nurses and social workers. This was colloquially referred to as community care and was supported by government policies such as 'Better Services for the Mentally Ill,'²¹ 'Care in the Community'²² and 'Community Care with Special Reference to Mentally Ill and Mentally Handicapped people'.²³ Numbers of residents of both mental health institutions as well as institutions for persons with intellectual disabilities dropped considerably in the 80s and 90s.²⁴

Reported inadequacies in community service provision for those individuals who had previously lived in asylums have provoked a great deal of debate over the last 50 years. However, the tone of this dialogue has changed. Early critics often cited that there were increased numbers of people with mental health problems who had become homeless after the closure of the asylums and cited this as evidence that community care had 'failed'. However, longer term studies of the outcomes for people who had spent many years living in the asylums have shown that the majority of people, even those with the most complex problems, have increased their social networks, gained independent living skills, improved their quality of life and have not required re-admission. The same is shown in studies about persons with an intellectual disability moving to forms of supported living in the community.

In Eastern European countries, deinstitutionalisation started to be implemented only after they joined the European Union in 2004 and EU Structural Funds became available to cover the costs of the transition.

As a result of a first attempt in Slovakia, the state invested almost 200 million euros between 2007 and 2011 into large and isolated residential institutions instead of community-based services.²⁸ Due to the negative feedback of the European Commission, a new development plan was created in 2011 with the participation of NGOs and key professionals.

In Hungary, the government planned to build new institutions with up to 150 beds using EU Structural Funds, but a relevant resistance of NGOs and professionals led to the withdrawal of the original call for proposals by the National Development Agency in 2009, and a new concept was developed by 2011.²⁹ On the other hand, researchers explored the fact that the Hungarian government has spent resources on building and renovating large institutions between 1996 and 2006, in spite

¹⁹ The information about the history of deinstitutionalisation in the U.K. has been taken from an extensive review study conducted by. Killaspy (2006). From the asylum to community care: learning from experience. *British Medical Bulletin* (2006) 79-80 (1): 245-258. doi: 10.1093/bmb/ldl017 First published online: January 23, 2007.

²⁰ Department of Health and Social Security 1971). Hospital Services for the Mentally Ill. London: HMSO.

²¹ Department of Health and Social Security (1975). Better Services for the Mentally Ill. London: HMSO.

²² Department of Health and Social Security (1981). Care in the Community. London: HMSO.

²³ House of Commons Social Services Committee (1985). *Community Care With Special Reference to Mentally Ill and Mentally Handicapped People*. London: HMSO. Department of Health and Social Security.

²⁴ Mansell J. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability* 2006; 31(2):65-76

²⁵ Coid J. (1994). Failures in community care: psychiatry's dilemma. Br Med J 1994;308,:805-806.

²⁶ Leff J. (1997). Care in the Community: Illusion or Reality? London: Wiley.

Leff J, Trieman N. (2000). Long stay patients discharged from psychiatric hospitals. Social and clinical outcomes after five years in the community. TAPS Project 46. *Br J Psychiatry* 2000;176:217-223.

Trieman N, Leff J. (2002). Long-term outcome of long-stay psychiatric inpatients considered unsuitable to live in the community: TAPS project 44. *Br J Psychiatry* 2002;181:428-432.

Thornicroft G, Bebbington P, Leff J. (2005). Outcomes for long-term patients one year after discharge from a psychiatric hospital. *Psychiatr Serv 2005*;56:1416-1422.

²⁷ Beadle-Brown, J., Mansell, J. and Kozma, A. (2007) Deinstitutionalization in intellectual disabilities. *Current Opinion in Psychiatry*, 20, 437-442.

²⁸ Monitoring of Absorption of Structural Funds in the Area of Social Services during the period of 2007-2011. INESS 2013.

²⁹ "One step forward, two steps backwards" Deinstitutionalisation of large institutions and promoting community-based living in Hungary through the use of the Structural Funds of the European Union. ELTE University 2011

of the fact that the first law on deinstitutionalisation was adopted in 1998.

In the study of the Institute of Public Policy, researches revealed that in Romania the emphasis was on the modernisation of existing residential institutions instead of the development of community-based alternatives during the period of 2007-2013. In their interviews, they explored the idea that the driving force behind projects to renovate large institutions was the need to ensure that institutions comply with the new quality standards, and Structural Funds seemed to be great opportunities to finance such works.³⁰

We found more consistent development work in the Czech Republic, where during the 2007-13 budgeting period preparation work was carried out to motivate and involve different stakeholders and to support users, professionals and regional municipalities.

In Estonia, the challenges of deinstitutionalisation were similar to other CEE countries. According to Kuuse and Toros (2017)³¹, despite the fact that community-based social welfare solutions have gained greater attention over time in various strategic documents, the results showed rather limited effect due the narrow and fragmented understanding and application of the deinstitutionalisation principles.

The impact of EU structural funds was, nevertheless, visible as the first wave of deinstitutionalisation was initiated with the support of the European Regional Fund and aimed at the closure of the large special care homes and substitute care homes for children. As a result, from 2007 until the end of 2015, 17 large institutions were reorganised into 88 family-type homes (33 for children and 55 for the special care sector). Nevertheless, in many cases those homes formed separate villages on the outskirts of the cities.

The European Social Fund resources were aimed at increasing labour market participation of people with special needs and their relatives through support to provision of mainly already existing various services at state and municipality level. In 2015, a small amount of the ESF funds were used directly to support the process of deinstitutionalisation, more precisely the concept paper for deinstitutionalisation was written and evaluation of 200 residents of special care homes was carried out. The outcome of the evaluation estimated the overuse of round-a-clock services, up to 1/3 of being in institutions could be dealt with on community-based services.

2014-20 Budget Period - the second wave of Deinstitutionalisation in the new member states

The European Union has recognised the problem of the misuse of Structural Funds by different Member States.

"On 20 November 2013, the European Parliament approved a new set of regulations governing the use of Structural Funds, referred to as the Cohesion Package 2014 – 2020. For the first time, the Structural Funds regulations include an explicit reference to the transition from institutional care to Community living, which falls within the thematic objective of "Promoting social inclusion and combating poverty and any discrimination" (Article 9 of the Common Provisions Regulation on the use of Structural Funds).

 (\dots)

The transition from institutional to community-based services is one of the aims of investments in health and social infrastructure under the European Regional Development Fund (ERDF). Only those actions that help to establish the conditions for independent living should be supported by the EU. Any measure contributing to

³⁰ Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living, European Network on Independent Living – European Coalition for Community Living, December 2013 http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf (last download 29th of August 2017)

³¹ Kuuse, R., Toros, K. (2017) Estonian social policy: from Soviet heritage to understanding the principles of deinstitutionalization. European Journal of Social Work. p. 1-12

further institutionalisation of disabled people or the elderly should not be supported by ESI Funds."32

Member States also recognised the failure of their former policies and they modified their development plans to some extent.

Slovakia and Hungary adopted new strategies for deinstitutionalisation in 2011. According to the Slovakian plans, 20 new pilot projects were supposed to be implemented by 2015 within the framework of the National action plan on the transformation of residential social services³³.

The implementation of the action plan has been problematic in Slovakia. Due to governmental changes and the lack of clear strategies at the level of local municipalities, a majority of the projects had massive delays.

Despite these problems, the deinstitutionalisation and development of community-based services has been slowly continuing and gradually expanding into all regions. To support this process, the Government also allocated resources from the Regional Operation Fund for the period of 2014-2020.³⁴

Hungary's new Strategy on Deinstitutionalisation consisted of a plan to transform residential care within a period of 30 years. As a result, new forms of housing services were proposed under the name of supported living, while the strategy maximised the capacity of new facilities in 50 beds. Still financed from the resources of the 2007-2013 budget period, 6 large institutions were selected for the first wave of deinstitutionalisation after the failure of the first plan in 2009.³⁵

For the period of 2014-20, the Hungarian Government plans to continue the implementation of deinstitutionalisation. Larger financial resources will be available during this period and a new development program has been initiated in order to develop community care. The principles of the new service structure include the following:

- Provide security while promoting the individual decision making of users (by introducing supported decision making).
- Person-centred and individually tailored services that lead to the enriched social capital of users.
- Network of services, co-ordination between different fields (social, health, vocational and cultural services).
- Accessible services that are available for everyone in their own community within a range of 20 km.
- Access to public transportation.
- In order to avoid the establishment of segregated "disability" districts or villages, the strategy maximises the number of disabled people living in housing services to 10% of the population of the given community.³⁶

In 2007, the Government of the Czech Republic adopted a document titled "Concept to Support the Transformation of Residential Social Services into Other Types of Social Services Provided in the User's Natural Community and Enhancing the User's Social Inclusion in Society". This strategic document determines objectives and measures to support the process of transformation and deinstitutionalisation, which is being implemented in the Czech Republic now.

³² Replies of the European Union to the list of Issues. June 2015.

³³ http://www.employment.gov.sk/files/legislativa/dokumenty-zoznamy-pod/narodny-plan-deinstitucionalizacie_en.pdf (last download: 29th of August 2017)

³⁴ Implementation of the United Nations Convention on the Rights of Persons with Disabilities in Slovakia. Alternative report of non-governmental and disability persons organizations. July 2015. http://www.mdac.org/sites/mdac.info/files/crpd_slovakia_alternative_report.pdf (last download: 29th of August 2017)

³⁵ Bugarszki, Zs., Eszik, O., Szentkatolnay M., Sziklai, I.: Deinstitutionalization and Promoting Community-Based Living in Hungary. ELTE University, 2011

³⁶ Fejlesztési koncepció-javaslat a fogyatékos személyek számára ápolást-gondozást nyújtó szociális intézményi férőhelyek kiváltásáról szóló stratégia (2011-2041) végrehajtásának elősegítéséről a 2015-2020. időszak tervezéséhez. Fogyatékos Személyek Esélyegyenlőségért Közhasznú Non-Profit Kft. Budapest 2015

³⁷ Resolution of the Government of the Czech Republic of 21 February 2007 No. 127.

The general aim of the project was based on detailed analyses of the current situation regarding social services, to arrange for a comprehensive system to support the transformation of such services, to prepare development plans, to raise awareness, to create a system of vertical and horizontal cooperation among all entities involved in the transformation process of institutional care, to support the process of enhancing the living conditions of users of today's residential social care facilities, and to foster the respect of the human rights of users of residential social services and their rights to enjoy a full life comparable to their peers living in a natural environment.³⁸

In a new phase, project outputs were channelled towards the pilot launch of the transformation process in selected toprisk facilities in all regions, under the conditions of cooperation with all stakeholders and the observance of principles of transformation process transparency.

In order to continue with the process of deinstitutionalisation, the Czech Republic has prepared a National Plan on Promoting Equal Opportunities for Persons with Disabilities for the Period 2015–2020, which mentions the following specific objectives and measures:

- Development of community services that reflect the needs of people with disabilities and assist in retention in their natural social environment; in response to a reduction in mass-residential facilities.
- Financing of social services that reflect the needs of people with disabilities and help to remain in their natural environment.
- Support for caregivers of persons with disabilities.
- Training and development of staff working in the social services.
- Supporting targeted public relations activities for major target groups.
- The reform of psychiatric care and its connection to the social services system.
- Social housing adapted for people with disabilities.
- Programs to "reintegrate" people with disabilities into the labour market.³⁹

In 2016, the government adopted the Social Welfare Development Plan 2016-2023⁴⁰, which defines the main aims and activities for employment and social policy. Among others, one of the objectives is "to develop the provision of social services, including improving the availability and quality of these services and emphasizing the services that support independent coping and life in society, as well as the de-institutionalisation of the welfare services system". The development plan acknowledges the principles of deinstutionalisation and foresees many activities and investments in that regard.

In the case of Estonia, the second wave of deinstitutionalisation continues the previously implemented strategy and builds on the experiences of the first wave. Approved plans foresee a continuation of investments into the special-care infrastructure with the aid of the European Regional Fund in the amount of 56 million euros until 2020, with the aim of modernising 1400 service places⁴¹. The support is provided for reorganising large institutions into facilities with no more than 30 service places and creating new community-based service places. The projects are expected to impact populated areas with at least 300 inhabitants, and the number of places can not exceed 10% of the local population⁴². According to the Social Welfare

³⁸ Initial Report of the Czech Republic to the UN Committee on the Rights of Persons with Disabilities. November 2011

³⁹ Replies of the Czech Republic to the list of issues. December 2014

⁴⁰ Ministry of Social Affairs (2016). Welfare Development Plan 2016-2023. http://www.sm.ee/sites/default/files/contenteditors/ees-margid_ja_tegevused/welfare_development_plan_2016-2023.pdf (last download: 29th of August 2017)

⁴¹ The Reorganisation of Special-Care Facilities. (2015). Retrieved May 22, 2016 from http://www.struktuurifondid.ee/public/Oige. pdf

⁴² https://www.riigiteataja.ee/akt/115092015022

plan for 2016-2023, the special care system is also going through a design process with the aim of testing and applying a new organisation of services more linked to the community.

With the support of the European Social Fund, major structural reforms are carried out, and one of the most important ones is the work ability reform, with estimated support from the ESF at around 170 million euros and an effect on around 100 000 citizens. Also, the further development of social services in local municipalities is supported by structural reforms⁴³

In the cases of Hungary, the Czech Republic and Slovakia, the first monitoring period has already been implemented and we could explore the Concluding Observations of the Committee.

Addressing the Hungarian government, the Committee took note that the State party has recognised the need for the replacement of large social institutions for persons with disabilities in community-based settings (deinstitutionalization). However, it noted with concern that the State party has set an extraordinary long, 30-year time frame for its plan for deinstitutionalization. The Committee was also concerned that Hungary has dedicated European Union funds, to the reconstruction of large institutions, which will lead to continued segregation.⁴⁴

As a recommendation:

"The Committee calls upon the State party to ensure that an adequate level of funding is made available to effectively enable persons with disabilities to: enjoy the freedom to choose their residence on an equal basis with others; access a full range of in-home, residential and other community services for daily life, including personal assistance; and enjoy reasonable accommodation with a view to supporting their inclusion in their local communities.

The Committee further calls upon the State party to re-examine the allocation of funds, including the regional funds obtained from the European Union, dedicated to the provision of support services for persons with disabilities and the structure and functioning of small community living centres, and to ensure full compliance with the provisions of article 19 of the Convention."45

In its Concluding Observations, the UN Committee also notes with concern that the Czech Republic invests more resources in institutional settings than into community care. The Committee urges the State party to allocate sufficient resources for the development of support services in the community. The Committee also recommends having a clear timeline with concrete benchmarks for the implementation of the National Plan on Promoting Equal Opportunities for Persons with Disabilities 2015-2020 in the Czech Republic.⁴⁶

In Slovakia, the Committee expressed its deep concern about the high number of institutionalised persons with disabilities, in particular women with disabilities. They noted that progress on the deinstitutionalisation process is too slow and there are ongoing investments from government budgets in institutions. They also pointed out that the lack of provision of full support for persons with disabilities to live independently in their communities hinders the successful implementation of deinstitutionalisation⁴⁷.

 $^{^{43}}$ http://www.sm.ee/et/struktuurivahendid-sotsiaalvaldkonnas-2014-2020#6.%20T%C3%B6%C3%B6v%C3%B5ime%20toetamise%20s%C3%BCsteemi%20k%C3%A4ivitamine

⁴⁴ Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (1728 September 2012)

 $^{^{45}}$ Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (1728 September 2012)

⁴⁶ Concluding observations on the initial report of the Czech Republic. May 2015.

⁴⁷ Concluding observations on the initial report of Slovakia. May 2016.

CONCLUSIONS

Seeing these controversial outcomes of deinstitutionalisation in Eastern Europe, it is not a surprise that the UN Monitoring Committee became very critical of the EU in their Concluding Observations.

"The Committee is concerned that across the European Union persons with disabilities, especially persons with intellectual and/or psychosocial disabilities still live in institutions rather than in local communities. It further notes that in spite of changes in regulations, in different Member States the ESI Funds continue being used for maintenance of residential institutions rather than for development of support services for persons with disabilities in local communities."

The Monitoring Committee not only expressed its concern that in spite of the ratification of the UNCRPD many people still live in large institutions in Europe but was very critical of the EU Commission, as it allowed using Structural Funds to maintain and develop large residential institutions.

In countries where deinstitutionalisation has been finalised over the last decades, the system has been remarkably shifted from institution-based solutions to community care. There is massive evidence of the positive outcome of independent living, and policy priorities are moving toward greater influence of user groups and user involvement, and toward an emphasis on recovery oriented, person centred approaches, followed by tailored financial schemes. However, we also need to recognise that economic turbulence and existing ideological or political debates on the role and content of the welfare state are affecting the well-established Western European model, too. In the UK and also in the Netherlands, we experienced severe austerity measures that may undermine the positive outcomes of former reforms.

In the new member states, access to EU structural funds brought an outstanding opportunity for a fundamental reform of the long-term care system, and in spite of the fact that this process has been started in all 5 examined countries, there is obvious tension between the principles of the United Nation Convention and the implementation of deinstitutionalisation. The importance of the second wave of deinstitutionalisation in the new member states is crucial, as it is hard to predict what kind of resources will be available for these countries in the next 2020-2027 budget period of the EU.

⁴⁸ Concluding observations on the initial report of the European Union. September 2015.