Deinstitutionalization and developing community based services

International overview

Zsolt Bugarszki, Hans van Ewijk, Jean-Pierre Wilken

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 deinstitutionalization 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 has implemented the first wave of deinstitutionalization and during the new EU budget period a second wave will be occurred in order to continue and hopefully complete the transition. In this study, we try to give an overview on the experiences of different European countries highlighting good practices and possible pitfalls.

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

Methodology

Our study is based on desk research 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 United Nations Convention on the Rights of Persons with Disabilities as a legal reference to the terminology and definition of deinstitutionalization and community living, while we consider the Guidelines of the European Expert Group[1] as a policy reference.

We selected 8 European countries to analyse:

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

The selected Eastern European countries can provide us with an opportunity to explore their progress and difficulties with the implementation of deinstitutionalization while the selected Western European countries can be analysed from the perspective of latest developments in community care.

In our desk 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

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

Persons with Disabilities. The Committee is a body of 18 independent experts[2] which monitors 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 summarize all their efforts they did 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 organized 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 three of the selected countries (Sweden, Czech Republic, Hungary) 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. We extended our analysis with the draft version of Estonia's first country report and we also had an overview on the monitoring process on the European Union as legal entity.

Table 1.: Monitoring 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	-	-	-
Sweden	Submitted	Submitted	Submitted	Published
The Netherlands	-	-	-	-
Czech Republic	Submitted	Submitted	Submitted	Published
Hungary	Submitted	Submitted	Submitted	Published
Slovakia	Submitted	-	-	-
Romania	-	-	-	-
Estonia	Draft	-	-	-
EU	Submitted	Submitted	Submitted	Published

In our analysis, we paid particular attention to the implementation of Article 19 that concentrates on the right living independently and being 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 deinstitutionalization.

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 on Skype or via e-mail using the method of semi-structured interviews.

[2] http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Membership.aspx (last download: 26th of September 2015)

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 Deinstitutionalization and Community Living

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

Article 19 of UNCRPD approaches the issue of independent living and community inclusion from the perspective or equal rights. It doesn't mention deinstitutionalization as a relevant policy to ensure these equal rights but put an emphasis on the desired outcome of any policy measures that have to aim at giving opportunity to 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]

[3] United Nation Convention on the Rights of Persons with Disabilities Article 19 http://www.un.org/disabilities/default.asp?id=279 (last download: 26th of September 2015)

The Guideline of the European Expert Group[4] describes in details the transition from institutional to community based care. To create a common sense, they defined institutions as the following:

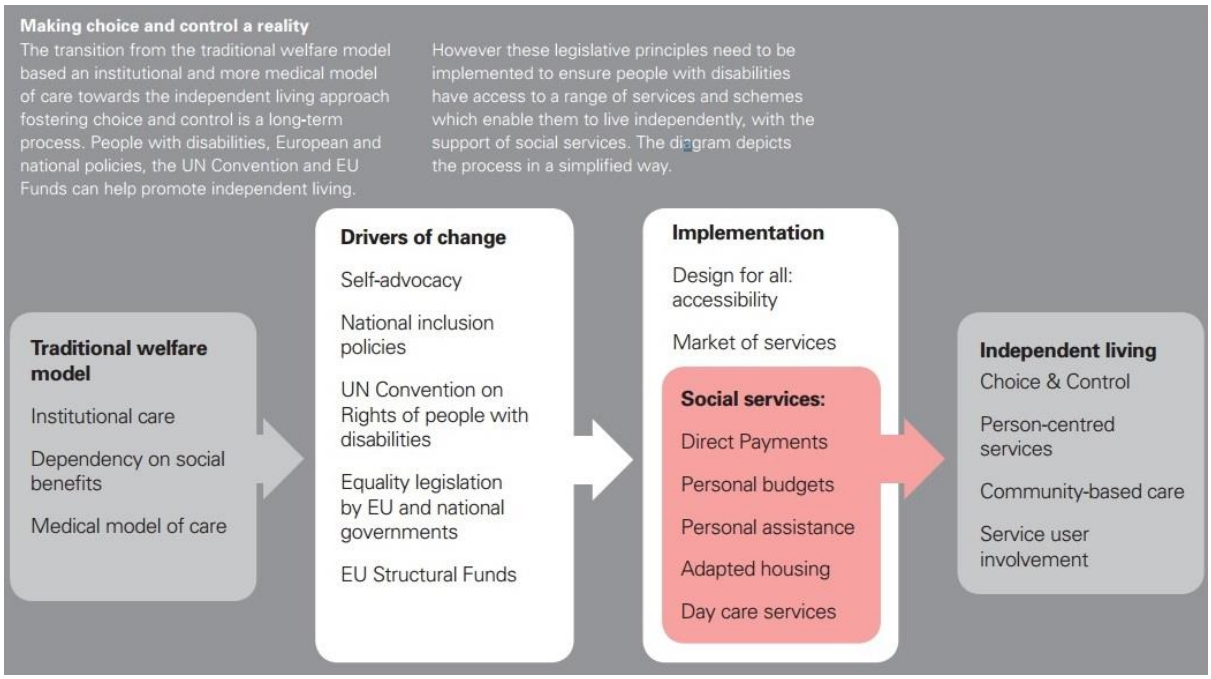
> *"There are different understandings of what constitutes 'an institution' or 'institutional care' depending on the country's legal and cultural framework. For this reason, the Guidelines use the same approach as in the Ad Hoc Report. Rather than defining an institution by size, i.e. the number of residents, 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;*
>
> *• 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 deinstitutionalization and identifying key elements for good community care.[6] ESN also published a report on how social services in different European countries are promoting choice and control alongside people with disabilities.[7]

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

[4] Common European Guidelines on the Transition from Institutional to Community Based Care http://deinstitutionalisationguide.eu/ (last download: 26th of September 2015)
[5] Common European Guidelines on the Transition from Institutional to Community Based Care p.25. http://deinstitutionalisationguide.eu/ (last download: 26th of September 2015)
[6] Developing Community Care – Report of European Social Network. 2011. Brigthon UK. http://www.esn-eu.org/developing-community-care/index.html (last download: 26th of September 2015)
[7] Independent living: making choice and control a reality – Report of European Social Network. 2011. Brighton UK.

Figure 1. The process of shifting from traditional welfare model toward 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 how different stakeholders interpreted the given legal frameworks and policy guides.

Due to the fact that there is no strict definition for institutions and institutional 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 board 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.

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.[9]

Romania didn't submit its initial report to the UN Committee yet, but in a report[10] of the European Coalition for Independent Living (ECCL) we could explore that the Romanian Institute for Public Policy considers as a fundamental problem the lack of clear objective in the national strategy for deinstitutionalisation. 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 requirement to replace existing residential institutions with community based services.

[8] http://www.independentliving.org/docs3/englss.html (last download 26th of September 2015)
[9] Initial Report of Slovakia to the UN Committee on the Rights of Persons with Disabilities. January 2012
[10] 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 26th of September 2015)

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."*[11]

In 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.[12]

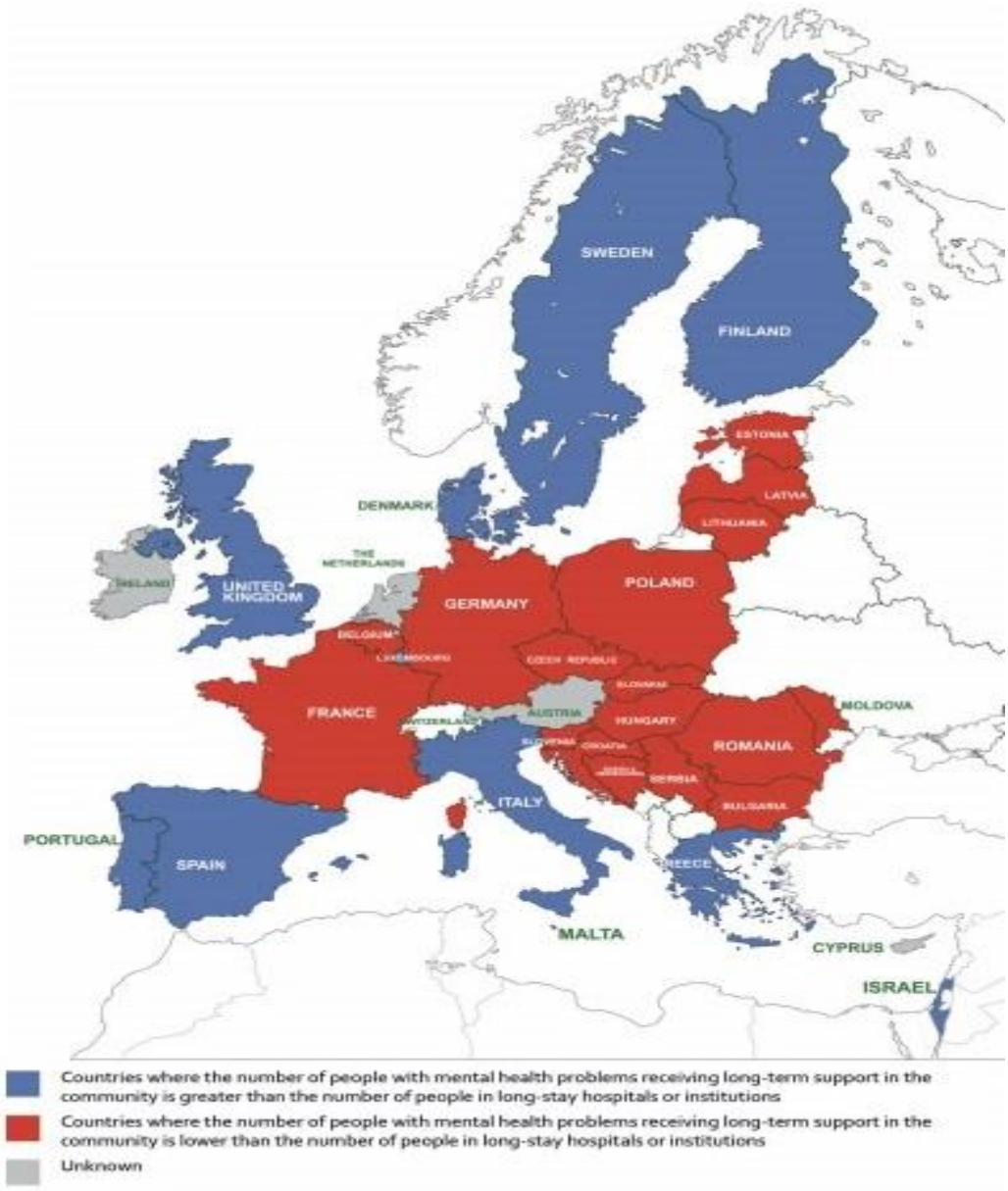
As we can see, while in Sweden community participation is emphasized, in the four Eastern European countries institutions are still considered as relevant part of the service system. In Slovakia, according to the government, community care enjoys priority but this is not reflected in the statistics.

In a study of Mental Health Europe researchers were exploring the proportion of mental health services to compare the weight of institutions and hospital care with service capacities in the community care. Authors revealed that in all the new member states (and in many Western European countries, too) institutional care is still considered as mainstream of the welfare services while community based services outnumber institutional care only in countries where the process of deinstitutionalization has already been implemented over the previous decades.[13] (see Map 1.) Similar results we would see also in disability care.

The lack of clear (operational) definition for community living and institutional care led to a wide variety of understanding and interpretation about Article 19 and the first wave of deinstitutionalization has been implemented based on these varying concepts.

[11] Initial Report of Hungary to the UN Committee on the Rights of Persons with Disabilities. October 2010
[12] Initial Report of the Czech Republic to the UN Committee on the Rights of Persons with Disabilities. November 2011
[13] Mapping Exlcusion. 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: 26th of September 2015)

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 deinstitutionalization

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 deinstitutionalization turned out to be a failure. The political decision on closing institutions has been made in 1993 and the process of deinstitutionalization 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 been occurred as there was an obvious commitment on behalf of all stakeholders toward deinstitutionalization, and they could rely on the experiences of other countries like Italy or the United Kingdom.

However, the first attempt of deinstitutionalization ended up as a failure as first community housing were rather group of group homes, and segregated "disability" blocks instead of real integration. Very soon it became obvious that situation of residents hasn'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 deinstitutionalization had been implemented in Sweden taking into consideration the principle of real community integration.[14]

Studies performed by Ravelli (2006) focused on how Dutch mental health care specifically developed toward deinstitutionalisation from 1993 to 2004 [49].[15] 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 are 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 till 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.

Dehospitalisation and decentralisation were the key concepts for the above processes. In practice, these concepts were translated into 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 bot intensive care and psychosocial support to persons with psychiatric disabilities living in the 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.

Supporting persons in the community with regard to self-care and participation is the main focus of the new Social Support Act, which became effective as of January 1st 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 elderly.

In the new system, only treatment and 24 hour care remains 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%.

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

[15] 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/

The number of persons with an intellectual disability in the Netherlands is estimated at approximately 110.000[16]. 26% of this group uses a form of residential care, while 14% receives a form of home care. institutions that provide care are independent non-profit private organisations that receive funding from the government[17]. Since 2015, a division is made between community services, like day centres, group homes and individual support, which are financed by the municipalities (Social Support Act), and facilities for 24 hours' care and supervision, which are funded centrally (Long Term Care Act).

The United Kingdom has a long tradition of deinstitutionalization and developing community based services[18]

In 1971, a Government paper on 'Hospital Services for the Mentally Ill'[19] 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',[20] 'Care in the Community'[21] and 'Community Care with Special Reference to Mentally Ill and Mentally Handicapped people'.[22]

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 tenor of this dialogue has altered. Early critics often cited that there were increased numbers of people with mental health problems who had become homeless secondary to the closure of the asylums and cited this as evidence that community care had 'failed'.[23] 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.[24]

---

[16] ANED (2009) The Netherlands – ANED country profile http://www.disabilityeurope.net/content/pdf/Netherlands%20ANED%20country%20profile.pdf In their report ANED cites estimates from the EU Monitoring and Advocacy Programme, Open Society Institute (2006) Rights of people with Intellectual Disabilities: Access to Education and Employment. Summary Reports, The Netherlands. Open Society Institute, Hungary. www.eumap.org http://www.osmhi.org/contentpics/202/id_nl.pdf

[17] Applica & CESEP & European Centre (2007) Study of the Compilation of Disability. Statistical Data from the Administrative registers of Members States.

[18] The information about the history of deinstitutionalisation in the U.K. has been taken from an extensive review study conducted by Helen Killaspy. Killaspy, H. (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.

[19] Department of Health and Social Security 1971). *Hospital Services for the Mentally Ill*. London: HMSO.

[20] Department of Health and Social Security (1975). *Better Services for the Mentally Ill*. London: HMSO.

[21] Department of Health and Social Security (1981). *Care in the Community.* London: HMSO.

[22] 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.

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

[24] 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.

In Eastern European countries deinstitutionalization started to be implemented only after their 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.[25] 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 up to 150 beds from EU Structural Funds but a relevant resistance of NGOs and professionals led to the withdrawal of the original call for proposal by the National Development Agency in 2009 and a new concept had been developed by 2011.[26] On the other hand researchers explored that Hungarian government has spent relevant resources on building and renovation of large institutions between 1996 and 2006 spite of the fact that the first law on deinstitutionalization 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 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.[27]

More consistent development work we found in the Czech Republic where during the 2007-13 budgeting period relevant preparation works occurred to motivate and involve different stakeholders and to support users, professionals and regional municipalities.

Seeing these controversial outcomes of the first wave of deinstitutionalization in Eastern Europe it is not a surprise that the UN Monitoring Committee became very critical toward 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."*[28]

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

[26] "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

[27] 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 26th of September 2015)

[28] Concluding observations on the initial report of the European Union. September 2015.

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

Preparing for the 2014-20 Budget Period – the second wave of Deinstitutionalization

The European Union also recognized 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).*
>
> *(…)*
>
> *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 further institutionalisation of disabled people or the elderly should not be supported by ESI Funds."*[29]

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

Slovakia and Hungary adopted new strategies for deinstitutionalization in 2011. According to the Slovakian plans 20 new pilot projects supposed to be implemented by 2015 within the framework of the National action plan on transformation of residential social services[30].

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

Despite these problems, 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 relevant resources from the Regional Operation Fund for the period of 2014 - 2020.[31]

Hungary's new Strategy on Deinstitutionalization consisted 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

[29] Replies of the European Union to the list of Issues. June 2015.
[30] http://www.employment.gov.sk/files/legislativa/dokumenty-zoznamy-pod/narodny-plan-deinstitucionalizacie_en.pdf (last download: 26th of September 2015)
[31] 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: 26th of September 2015)

supported living while the strategy maximized the capacity of new facilities in 50 beds. Still financed from resources of the 2007-2013 budget period, 6 large institutions were selected for the first wave of deinstitutionalization after the failure of the first plan in 2009.[32]

For the period of 2014-20 Hungarian Government plans to continue the implementation of deinstitutionalization. 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:

- Provides security while promotes individual decision making of users (by introducing supported decision making)
- Person centred and individually tailored services that lead to enriched social capita 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 maximizes the number of disabled people living in housing services in 10% of the population of the given community.[33]

In 2007, the Government of the Czech Republic has 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".[34] This strategic document determines objectives and measures to support the process of transformation and deinstitutionalization which is, practically, being implemented in the Czech Republic now.

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 fulfilment of human rights of users of residential social services and their rights to enjoy a full life comparable to their peers living in natural environment.[35]

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

In order to continue in the process of deinstitutionalization, 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:

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

[33] 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 Esélyegyenlőségéért Közhasznú Non-Profit Kft. Budapest 2015

[34] Resolution of the Government of the Czech Republic of 21 February 2007 No. 127.

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

- 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.[36]

The UN Monitoring Committee evaluated the implementation of UNCRPD not only at the level of the EU but they also examined member states that have ratified the convention. In case of Hungary and the Czech Republic the first monitoring period has already been implemented and we could explore the Concluding Observations of the Committee.

Addressing to the Hungarian government the Committee took note that the State party has recognized 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.[37]

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."*[38]

In its Concluding Observations, the UN Committee also notes with concern that the Czech Republic invest 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 to have a clear timeline with concrete benchmarks for the

[36] Replies of the Czech Republic to the list of issues. December 2014
[37] Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012)
[38] Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012)

implementation of the National Plan on Promoting Equal Opportunities for Persons with Disabilities 2015-2020 in the Czech Republic.[39]

Developing community based services

Regulation of community based services – shared responsibilities

Deinstitutionalization shifts resources from centralized, institutional services to local, community based solutions. However, the dynamics of sharing responsibilities between different stakeholders shows a bit more complex picture. As we could see it in the study of Mental Health Europe (see Map 1.), in the new member states institution and hospital based care takes the majority of resources while community based alternatives are continuously growing from a low base at a moderate pace. At the moment, we can state that Eastern European countries (and many Western European countries, too) are still characterized mostly by traditional institution based care.

Large institutions in most of the Eastern European countries were maintained on county/regional level which is an intermediate level between local municipalities and the central government. Ministries, governmental bodies rarely took direct responsibilities to act as service providers but on the other hand the finance of large institutions arrived mostly from the central budget, usually as an entitled money. This we can call a semi-decentralization where regional governments were involved as service providers but the regulation and finance of the institutions in fact belonged to the central government.

Local municipalities are usually responsible for community-based services with larger freedom to decide which services they establish (or rather neglect) and what kind of own solutions they introduce.

In 2004, eleven years after the introduction of the first Social Service Act a study revealed that only 4% of Hungary's more than 3200 local governments have established all the social services described in the legislation.[40]

Spite of the larger independence the financial structure seems to be similar here, as only a very few local governments[41] could afford to run their community-based services on their own. After all we find the state, and central government behind the entire service structure when it comes to finance.

In some Western European countries, this mechanism shows more diversity. In Sweden and to some extend in the United Kingdom local governments have more (financial) independence to shape their care system. In the field of mental health and disability care we found strongly centralized solutions in the Netherlands where until recently all special care services were financed by the central government directly regardless the location of services. Within the framework of a comprehensive welfare reform this system started to be decentralized in the Netherlands, too. Since the beginning of 2015, most responsibilities (including budgets) have been shifted from a national level to a local level, putting the municipalities in charge of social services, supported housing, youth care and labour participation. Each local authority has the liberty to shape the services according to their own policy.

Sharing responsibility for care between the government and municipalities caused tension in many Eastern European countries. Decentralization and autonomy of local communities was a vital element of the newly established democracies in the region which is an obvious political achievement but the

[39] Concluding observations on the initial report of the Czech Republic. May 2015.
[40] Bugarszki, Zs.: A szociális szolgáltatások újjászületése Magyarországon. ESÉLY 2004/4 Budapest 2004
[41] Large cities, local governments of prospering industrial or business areas

sustainability of the municipalities remained a question during the whole period. Lack of resources led to an unfortunate practice in the care system. Local governments instead of establishing community-based services that might provide relevant support for vulnerable people preferred to refer them to regional/country services (namely to institutions). That created growing demand for institutions and left less resources to develop community based services which resulted further institutionalization. We could explore this phenomenon in every Eastern European country in our research.

When the process of deinstitutionalization has started in Eastern Europe the tension between central governments and local municipalities were already there in the care system. Both local and regional governments were fighting for their position while central governments were usually obligated by international treaties signed and ratified by their parliaments. We discovered different strategies to handle the tension between stakeholders. In Hungary, the government, has decided to centralize the management of all large institutions excluding county governments from the service system. A centralization like this created more optimal position for deinstitutionalization as instead of negotiating with 19 different county municipalities government needed to deal with only one board of managers leading a government established national organization. Similar mechanisms were followed with local governments when in Hungary they changed the legislation delegating the two most important community-based services to the responsibility of the government excluding local governments from the picture. Service providers had to apply for support directly to a governmental body in order to receive funds from all over the country. We found that this kind of centralization resulted the exclusion of very important local partners but on the other hand led to a more optimal allocation of basic services providing an almost full coverage in the country. Services are more stable but the system is less democratic.[42]

A totally different approach was chosen in the Czech Republic where they didn't start to implement any reforms until all the stakeholders (including regional and local municipalities) got convinced to support and participate in deinstitutionalization. Training activities, motivating incentives, involvement into preparation and implementation were the key element of the strategy and they started to close down large institutions only after each participant started to support the reforms. During the budget period of 2007-2013, most of the EU Structural Fund resources were spent on this preparation works in the Czech Republic.[43]

In Estonia, we explored similar tensions between central government and local municipalities. During the first wave of deinstitutionalization a certain type of centralization has occurred. By establishing one large service provider (AS Hoolekandeteenused) majority of the large institutions became under one roof but in Estonia community based services remained in the hand of local governments. Organizing large institutions together is definitely a good solution to manage their closure easier. But this solution doesn't solve the problem of the involvement of each stakeholder. Without a commitment and participation of local municipalities we can't implement deinstitutionalization. Whatever services large service providers establish in the community, if local municipalities are not part of it, they will be never integrated part of the local support network. We rather recommend to follow the Czech way for the second wave of deinstitutionalization involving intensively local municipalities and making them responsible for integration. We also have to make sure that local partners also will have access to EU development resources and large flexibility to shape their future support system according to their local circumstances. The involvement of local NGOs, innovative initiatives and especially user led organizations is also very important to utilize all the existing

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

[43] Replies of the Czech Republic to the list of issues. December 2014

resources in the community. Deinstitutionalization can't be an administrative issue of a few chosen stakeholders.

Service provision

In the United Kingdom, the implementation of the Care Programme Approach (CPA),[44] which is still a fundamental framework within which mental health services operate, attempted to improve continuity of care for people with mental health problems. All patients considered appropriate for the CPA have an identified professional who co-ordinates their community care package and who arranges regular reviews of their care with other professionals including their consultant psychiatrist.

In addition, the National Service Framework for Mental Health[45] and the National Health Services Plan[46] detailed the development of a number of new community mental health services. Two of the three new models, early intervention services and crisis resolution teams, have both been shown to reduce the likelihood of admission when compared with community mental health team care and to lead to improved patient satisfaction with services.[47] However, assertive outreach teams have not been found to be able to reduce admissions in the UK [48] despite good evidence for their efficacy in this regard in the USA and Australia.[49]

In 2011, a new mental health strategy for England was published, with a focus on quality of services, recovery. Physical health, human rights and anti-stigma / discrimination.[50] The strategy was widely welcomed, but the economic recession of the past three years has led to significant extra pressures on parts of the population (including threat of loss of job and housing, and increased levels of debt) that has led to an increase in reported common mental disorders, and the suicide rate has risen. At the same time, public service spending restraints have led to cuts in NHS and local authority services that are severely challenging the ability of the new strategy to achieve its intended objectives.[51]

As inpatient bed use is the most expensive component of health care, community alternatives can appear attractive and potentially cheaper. However, Macpherson *et al.*'s review of supported

---

[44] Department of Health (1990). *The Care Programme Approach for People with a Mental Illness Referred to the Specialist Psychiatric Services.* London: HMSO.
Department of Health (1989). *Modernising the Care Programme Approach: Effective Co-ordination of Mental Health Services.* London: HMSO.

[45] Department of Health (1999). *National Service Framework for Mental Health: Modern Standards and Service Models.* London: HMSO.

[46] Department of Health (2000). *NHS Plan.* London: Department of Health.

[47] Craig T, Garety P, Power P et al (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *Br Med J 2004*;329:1067. doi:10.1136/bmj.38246.594873.7C; doi:10.1136/bmj.38246.594873.7C.
Johnson S, Nolan F, Pilling S, et al (2005). Randomised controlled trial of acute mental health care by a crisis resolution team: the north Islington crisis study. *Br Med J 2005*;331:599. doi: 10.1136/bmj.38519.678148.8F; doi: 10.1136/bmj.38519.678148.8F.

[48] Killaspy H, Bebbington P, Blizard R, et al (2006). The REACT study: randomised evaluation of assertive community treatment in north London. *Br Med J 2006*;332:815-820. doi: 10.1136/bmj.38773.518322.7C; doi: 10.1136/bmj.38773.518322.7C.
Glover G, Arts G, Babu KS (2006). Crisis resolution/home treatment teams and psychiatric admission rates in England. *Br J Psychiatry 2006*;189:441-445.

[49] Marshall M, Lockwood A. (1998). Assertive community treatment for people with severe mental disorders (Cochrane review). In the Cochrane Library. (Issue 4).

[50] Department of Health (2011) *No Health Without Mental Health: a cross-government mental health outcomes strategy for people of all ages.* London: Department of Health.

[51] Lawton-Smith, S., McCulloch, A. (2013). *A brief history of specialist mental health services.* London: Mental Health Foundation.

accommodation for people with severe mental illness[52] included reference to an investigation of the costs associated with hospital-based and community-based mental health care. This concluded that appropriate community care is not a cheaper alternative to hospital care and that the costs associated with caring for those with high levels of need in the community may be greater than hospital care. In line with this, McCrone *et al.* compared two geographical areas, one of which had more intensive community mental health services than the other area, and found that services provided to clients in the intensive area cost more than those in the standard area and that older age and higher levels of disability were associated with higher costs.[53]

The evidence from this review suggests that a number of areas should be given attention when services shift from hospital-based to community-based models of care. It is obvious that community services cannot completely replace hospital care. In fact, Thornicroft and Tansella's review of community mental health service provision clarifies that a balanced service includes inpatient beds, although the number of beds inversely reflects the quantity and quality of community resources available.[54] They conclude that to enable a balanced system to work, resources from reductions in inpatient services should be invested into community services. In other words, community services are not cheaper alternatives to hospital-based services, but should be seen as part of a whole system. Therefore, the focus on inpatient bed use as a measure of efficacy needs to be considered in the context of its integral role within this system, accepting that it is the most expensive element of care.

The evidence presented highlights some benefits of community-based care, which are consistent across specialties such as greater client satisfaction and quality of life.[55]

A study that investigated the characteristics of good community care for people with severe mental illnesses from the perspectives of clients, families, professionals, policy makers and other citizens in five European countries found that the most important characteristic was a trusting and stimulating relationship between clients and professionals. Effective treatment tailored to individual needs and accessibility of services was also highly rated.[56] These factors are clearly relevant to all clients, irrespective of their health needs and the location of their treatment.

---

[52] Macpherson R, Shepherd G, Edwards T. (2004). Supported accommodation for people with severe mental illness: a review. *Adv Psychiatr Treat 2004;*10:180-188. Chisholm D, Hallam A (2001). Changes to the hospital-community balance of mental health care: economic evidence from two UK studies. In Brenner H, Boeher W (eds), *The Treatment of Schizophrenia—Status and Emerging Trends*, Kirkland: Hogrefe & Huber, 210–224.

[53] McCrone P, Johnson S, Thornicroft G. (2001). Predicting the costs of community care for individuals with severe mental illness in South London. *Schizophr Bull 2001*;27:653-660.

[54] Thornicroft G, Tansella M. (2004). Components of a modern mental health service: a pragmatic balance of community and hospital care. *Br J Psychiatry 2004*;185:283-290.

[55] Craig T, Garety P, Power P, et al. (2004).The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *Br Med J 2004*;329:1067 doi:10.1136/bmj.38246.594873.7C; doi:10.1136/bmj.38246.594873.7C.
Johnson S, Nolan F, Pilling S, et al. (2005). Randomised controlled trial of acute mental health care by a crisis resolution team: the north Islington crisis study. Br Med J 2005;331:599. doi: 10.1136/bmj.38519.678148.8F; doi: 10.1136/bmj.38519.678148.8F.
Killaspy H, Bebbington P, Blizard R, et al. (2006). The REACT study: randomised evaluation of assertive community treatment in north London. *Br Med J 2006*;332:815-820. doi: 10.1136/bmj.38773.518322.7C; doi: 10.1136/bmj.38773.518322.7C.

[56] Van Weeghel J, van Audenhove C, Colucci M, Garanis-Papadatos T, Liegeois A, McCulloch A, et al. (2005). The components of good community care for people with severe mental illnesses: views of stakeholders in five European countries. *Psychiatr Rehabil J 2005*;28:274-281.

When we look at the service structure of community based services we can find more or less the same types of social and health services in Eastern Europe. Acute treatment is usually hospital based or in some countries (Hungary and Czech Republic) we also found effective network of ambulant health services. Mobile crisis teams, small crisis facilities and multidisciplinary solutions combining social and health professionals are very weak in Eastern Europe.

Health care professionals are employed in large scale hospitals and they are not motivated to reduce the number of beds in facilities where they work. Health care providers receive the highest reimbursement when the occupancy in their facilities is maximized. Patients remain virtually silent and political leaders are satisfied with the provided level of care, which is cheap and does not invite massive complaints.

There is a weak relationship between medical and social services that causes problems especially in mental health care. Over the last 25 years' relevant development has occurred in the field of community based social services creating a complementary system to medical care with an unfortunate low level of interaction between the two systems. The problem is very relevant in Hungary in Romania and in the Czech Republic and to some extend we realized this issue in Estonia, too. In Estonia, the shift from medical paradigm to a psychosocial approach seems to be more characteristic but it doesn't mean that the co-operation between medical and social professionals is any stronger.

Typical social services in community based mental health and disability care are supported living programmes, day care centres, counselling, case management, different rehabilitation and vocational rehabilitation services with very diverse capacities and quality. None of the Eastern European countries can be described at the moment as countries running predominantly community based services.

In an international research programme, conducted by 4 European Universities including TLU, we found that current community based services are rarely connected to local communities. The service system is fragmented to serve different target groups and instead of strengthening cohesion and participation on the level of local communities our existing services are creating new segregation within the community providing separate living, working and leisure areas for elderly, disabled or mentally ill. Sheltered houses in isolated regions, sheltered workplaces for disable only and day care centres designed to dedicated target groups only do not really support community integration even if these services are located in the neighbourhood. [57]

We found innovative solutions to these problems in the Netherlands and in the Czech Republic. In Amersfoort, local authorities decided to close many specialised day care centres connecting users with more integrated community centres and they delegated more responsibility to the network of local neighbourhood instead of solving every problem with welfare services. Solutions like this – mobilizing existing community resources – can be useful in Eastern European countries where the level of social expenditures are definitely lower and there is very little chance to establish professional social services in every settle. However, in our research[58] we found that social cohesion in Eastern European

[57] Wilken, J. P.; Hanga, K. (ed) Stories of Recovery and Participation – experiences and challenges. Institute of Social Work Tallinn University. Tallinn 2015

[58] Wilken, J. P.; Hanga, K. (ed) Stories of Recovery and Participation – experiences and challenges. Institute of Social Work Tallinn University. Tallinn 2015

countries are weak. Strengthening local communities must be a priority for future welfare services in mental health and disability care.

In the Czech Republic, we explored a very fruitful combination of social services and social enterprises. In Prague, there are hundreds of cafes, stores, gardening companies, computer or bicycle repair saloons and even larger services as hotels, travel agencies run by disabled people or people with mental health problems. Social enterprises not only provide relevant income to service providers but also proved to be excellent rehabilitation tools to develop new identities beyond disability.

There is a growing tendency to use innovative ICT developments in service provision. E-services like e-counselling or virtual youth centres are not only excellent solutions to reach remote areas but also proven their effectiveness in care.[59] Very promising new initiatives are modern sharing economy models that provide peer to peer solutions empowering ordinary people by giving them the opportunity to turn themselves into micro-entrepreneurs and active participants of their local community. Food banks, food swap platforms, community platforms, favour banks, gig economy are relevant options for disadvantaged groups who usually have limited access to community or business resources. Online solutions and modern network societies can bypass these disadvantages by increasing social capital of vulnerable people.

Estonia is a country where social expenditures is one of the lowest in the European Union. In the near future, we do not expect that this situation will be changed. Therefore, we see little chance to create a traditional welfare system in Estonia where professional welfare services will take over the responsibility of care from families and local communities. The current level of taxation and the low redistribution rate of the country results limited capacities in the welfare system and we do not recommend to rely on EU resources on a long term to finance social services.

Our recommendation is to establish a sustainable co-operation between the state, local communities, businesses and individuals in order to create an inclusive society. A clear division is needed between the role of the central government and the role of local municipalities. In the Netherlands and Sweden medical care is organised and financed on a national level, while all forms of social care for persons with disabilities are the responsibility of local authorities. When it comes to social care a strong connection is needed between social support services and participation in different domains of life. We recommend a similar solution for Estonia. State still have an obvious and relevant role to take care of people in need but the role of state is rather to stimulate and mobilize community resources instead of replacing them. We fund very strong arguments analysing the current welfare reforms in the Netherlands that even in a well-established welfare state social expenditures are not sustainable if care relies only on professional services.

[59] Alleman, J. R. (2002). Online counseling: The internet and mental health treatment. Psychotherapy, 39, 199-209

The finance of community based services

Financial issues are closely related to the above-mentioned dimension of shared responsibility between different stake holders. There are five principal challenges facing Europe's mental health systems[60] and most of the points are applicable for disability care, too.

1. Resource insufficiency. Not enough financial and other resources are made available for mental health. Many countries are struggling with recurring financial imbalances between revenues and expenditures as they prepare for long-term sustainability of social and health systems, as well as long-term care. Increased private financing to a large extent, including cost-sharing by consumers and relatives, is inevitable. Considering the burden of mental illness, resources allocated to mental health are insufficient.

Resource insufficiency is an existing problem in Estonia, too. The burden of mental health problems and disabilities shows a growing tendency while we can't see relevant capacity development in this field. Deinstitutionalization needs to be implemented with relevant capacity buildings in the community with additional resources allocated to mental health and disability.

2. Resource distribution. Available services are poorly distributed. For example, a large portion of services are located in large cities while entire regions are uncovered. As local municipalities are generally financed based on their population big cities and larger towns are pulling not only people but also resources from local communities.

The planned local government reform in Estonia may help to solve these issues creating more sustainable communities.

3. Resource inappropriateness. Available resources do not match the needs of the population. Psychiatric hospitals or large 24 hours care institutions consume resources that should be invested in the development of community-based services. Another issue is that we found large consumption on services like physiotherapy and counselling while we are not convinced that these services are responding to the basic needs of service users in life domains like housing, independent living or vocational skills.

In her PhD research on the Estonian rehabilitation system Karin Hanga clearly proves that there is a mismatch between what people need and what the system is providing. Being aware of limited resources in the welfare system we have to make sure that we spend on services because they are needed and not because they are listed in the legislation. The current finance and reimbursement systems do not support the desired changes in resource allocation.

4. Resource inflexibility. Rigidly organized services are unable to respond to individual and community needs. Finance and reimbursement protocols do not offer incentives to improve flexibility in resource use. In fact, the budget mechanisms tend to preserve the existing structure of services. Finding ways to finance new alternative (community) services is very difficult. Social work need to be a creative and responsive profession; if we close services into protocols very little space will remain to solve real problems.

[60] Knapp, M.; Funk, M.; Curran, C.; Prince, M.; Grigg, M.; McDaid, D. Economic barriers to better mental health practice and policy. Health Policy Plan. 2006 May;21(3):157-70.

In Estonia, we still find central regulation of every elements of social services as a mainstream solution. There is very little space for unique and creative local solutions. Expecting more responsibility on local level need to be paired with more flexibility to address problems locally.

5. Resource dislocation. Available health and social care services for people with mental illness are poorly coordinated. There is a lack of financing and reimbursement to pay services at the boundary of the health and social systems, and motivate better coordination of services.

While case management as one of the core services in community care exists in Estonia it doesn't have the same function of co-ordination as it is in different case management models all over the world. Institutional care is a one-dimensional model where all needs are met at one place while community-based solutions are operating with more fragmented service elements creating individual portfolio of support for each user. Co-ordination of this care is very important from both financial and rehabilitation perspective.

In close relation with the growing influence of users on their own care and to shift from service centred solutions to person centred ones, lately we can see more emphasis on direct payment schemes in service finance.

In the Netherlands people with disabilities have the possibility to get a Personal Care Budget. In this case, they are paying for the services they use. It is also possible to get a budget which is paid directly to the service provider.[61]

The government also states that it is society's responsibility and the personal responsibility of people with disabilities to create a more inclusive society. The introduction of the Social Support Act in 200 and the revised Act in 2015, exemplifies this policy in that it emphasises the importance of independent living and transfers the provision of support and care from the national level to the local governmental level, i.e. the municipalities. In the last decade, the Dutch government has introduced policy measures to increase the number of people with disabilities participating in employment (including mainstream, fulltime, part-time, and supported employment).

It is estimated that in England around 1,2 million people have learning disabilities[62]. The majority is living in the community. 12% are using some kind of special accommodation, including hospital care. Local authorities are responsible for residential services. Around 110.000 adults use local authority-funded community services. 43.000 persons are making use of a direct payment and/or personal budget (which is called self-directed support). In 2010/11, local authorities were spending £260 million on direct payments for adults with learning disabilities, an annual increase of 40% per year from 2005/06 after considering inflation 380.000 adults with learning disabilities are receiving Disabled Living Allowance. The number of people with learning disabilities who are claiming Disability Living Allowance has increased by just over 5% per year over the past 10 years.

[61] Health and Personal Social Services for People with Disabilities in The Netherlands. A Contemporary Developments in Disability Services Paper. NDA, 2011. Retrieved October 2015: http://nda.ie/Policy-and-research/Research/Research-publications/Developing-Services-for-People-with-Disabilities/Health-and-Personal-Social-Services-for-People-with-Disabilities-in-The-Netherlands/

[62] Emerson, E., Hatton, Chr., Robertson, J., Roberts, H., Baines, S & Glover, G. (2010).*People with Learning Disabilities in England 2010*. London: Department of Health. Emerson, E., Hatton, Chr., Robertson, J., Roberts, H., Baines, S & Glover, G. (2011).*People with Learning Disabilities in England 2011*. London: Department of Health.

Before, personal budgeting and any kind of direct payment solutions) rather belonged to Scandinavian or Western European countries but now we found them to be introduced in the Czech Republic and Slovakia, too.

In the Czech Republic, disability activists called for a direct payment scheme as one of the main pillars of the new legislation on social services and at present a radical change in the financing of social services has been taking place by shifting from a bed-funding or place-funding scheme toward a direct payment scheme.

Persons who need assistance by other people in their everyday lives because of their age or state of health are provided with care allowance to enhance the competences of these persons and the caring environment so that everyone may chose individually the most practical and useful way of meeting their needs. This benefit is provided with a view to ensuring necessary assistance both informally (such as by a family member or neighbour) or formally (such as by a registered provider of social services). The care allowance is provided in four degrees according to the level of dependency of the person in need of assistance by other person which is established by a medical assessment and social survey. In line with the established level of dependency, the level of financial support is differentiated as well. In addition, there is difference between persons under the age of 18 and persons over the age of 18.

Assistance must be based on individually determined needs of the persons, it has to stimulate them, foster the development of their independence, motivate them to such activities that do not result in long-term stagnation or deterioration of their unfavourable social situation, and it should enhance their social inclusion.

Such financial mechanism allows social services to react flexibly to the needs of their users creating a wide-ranging offer of individual types of social services from which a person may chose freely as they may consider appropriate, according to their financial situation or other individual preferences. This solution also creates space for participation in the decision-making process regarding the extent, types and accessibility of social services in their municipality or region.

Introducing direct payment schemes relevantly increased the independence of users and led to more person-centred attitude at social services but we also discovered challenges. In case of financial difficulties governments tend to cut these expenditures as we can see it happening currently in the United Kingdom or in Finland. In Sweden, legislation obligates local municipalities to create competition between service providers giving real choice for users, and high level of user involvement is guaranteed in every aspect of care and care design.

In the Czech Republic, direct payment scheme caused an unexpected burden on the state budget. There is a criticism that the real costs of the new scheme were not properly calculated (Hanzl, 2010). The number of persons being entitled to a contribution for care was much higher than expected. It is also clear that the amount of contribution for care does not fully cover the real costs of the services provided. Thus, service providers, NGOs and institutions governed mainly by regional authorities, are facing serious financial difficulties to maintain their provisions and have to look for additional recourses.

Although major changes inside the financing system occurred by the introduction of the direct payments, no significant improvements of choice and control could be identified for people with intellectual disabilities[63].

[63] Šiška, J., July Beadl-Brown (2011). Developments in Deinstitutionalization and Community Living in the Czech Republic. Journal of Policy and Practice in Intellectual Disabilities Volume 8 Number 2 pp 125–133.

In addition, new schemes such as citizen advocacy, a different understanding of guardianship, greater involvement of social workers, supported decision-making, and a combination of person-centred planning and individual financing should contribute to preventing such difficulties.

The uniqueness of personal assistance resides in the fact that people with disabilities can choose who they want to work for them, organising support and scheduling the times when they need it. This means controlling and managing the whole process (Evans, 2003; Zarb, 2004; Morris, 2004). Choice and control over personal assistance support services is usually non-existent when operating under organisations who have little understanding of the principles of independent living, and using direct payments in ways that do not give choice and control to people with intellectual disabilities (Morris, 2004). Poor payment of personal assistants who can support individuals with disabilities limit the quality of service provided (Morris, 2004; Zarb, 2004).

In Estonia, we recommend to rely on a comprehensive co-finance structure with more relevant involvement of local municipalities, users and carers. Instead of considering finance as a transaction between the state (or different level municipalities) and service providers we recommend to rely on a multi-party scheme acknowledging the impact and responsibility of each involved parties. We propose a model with an emphasis on the individuals and the community. Individuals can be empowered by having the means necessary to live and to purchase services they need. Local communities need to be stimulated and empowered to create a more 'caring and inclusive community' and for this they need to receive resources from the state.

We hope that as a result of the planned local government reforms we will find stronger, more sustainable local municipalities in Estonia and those will be capable to shape their own communities. On the other hand, we need to clarify that if support for vulnerable people in the community are the mandate of local municipalities there is no option to refer people to large (centrally or regionally financed) institutions. Hospital care, crisis and special forensic facilities are still needed to be part of the care system but they do not have to be large. Municipalities are responsible for their local citizens. To be able to fulfil their duty local municipalities needs to have the flexibility to organize support networks according to their local circumstances instead of following protocols and regulations.

The same way with a well targeted direct payment scheme service users can be encouraged as purchasers of services taking over the control of their own care supporting them with the method of supported decision making mechanism instead of the traditional guardian system. We agree that only a smart combination of user involvement, user participation, supported decision making mechanism with restored legal capacities and a well targeted but still flexible direct payment scheme in a locally co-ordinated support system can lead to independent living in the community. To introduce these elements, we need paradigm change in the Estonian service finance mechanism and legal capacity system for disabled people.

Employment

From economic perspective one of the most important element of the ongoing reforms is to increase employment rate among people with disabilities and mental health problems. Employment is very important element of independent living. A job provides strong identity in the community and a stable income contributes to sustainable, independent life.

We found very controversial solutions in Eastern European countries to increase integration of vulnerable people into the labour market. While in the Czech Republic we find a very rich and effective tradition of social enterprises that are aiming at successful employment on the open labour market in

Hungary and Romania mainstream vocational services are sheltered workplaces that are usually donated by the state.

Social Policy Research Institute "Budapest Institute" has conducted a research on the effectiveness of different vocational rehabilitation services in Hungary and they found that integrated solutions that support employment on the open labour market are more effective as any subsidised sheltered workplaces or so called work therapies in isolated settings.[64]

In Estonia, we found only a few examples of sheltered workplaces, the majority of vocational rehabilitation programs are aiming at labour market integration. However, the employment rate among disabled people is still much lower than as it is in the general population.[65]

To increase employment rate Estonia has introduced Work Ability reforms changing the assessment system and introducing new services to mobilize people with disabilities and reduced working capacity to the labour market. The implementation of the reforms has been postponed twice and until now we still know very little about the planned new services. Labour offices (Töötukassa) will play a central role in this process while many vocational services will be outsourced to local partners and services providers.

In our interviews, we explored some uncertainties regarding the planned reforms. Labour offices sense the large responsibility for an enormous task with disabled people they have little experience with, while local service providers, NGOs and experienced professionals are concerned how they will be involved into the implementation of the reforms.

On behalf of employers we also discovered serious concerns regarding employment of people with disabilities. Supporting people with physical impairments seems to be manageable for many employers, people with intellectual disabilities or mental health problems face more challenges. Job opportunities are simply not flexible enough for them that leads to drops and quits very often. Employers are concerned about reliability and endurance of these people while the tax system, regulations and the available incentives and support opportunities doesn't really promote flexible solutions (part time jobs, home based work, flexible workloads and creative replacement solutions).

We also discovered serious complains about the enormous bureaucracy around available services and support opportunities. Some of our interviewees expressed that after they applied for support in order to employ people with disabilities but the administration of the process was so difficult that they decided not to apply anymore.

In the international literature, we find good examples ~~practice there are~~ of flexible and creative solutions how to mobilize vulnerable people on the labour market. Modern job coaching services within the framework of supported employment programs are providing a wide variety of training and practice opportunities combined with transitional employment or social enterprises that very often lead to job opportunities on the opened labour market. Job coaches similar to case managers are guiding and supporting people not only to get a job, but also to keep it. There are many examples for complex rehabilitation processes promoting recovery and labour market integration for people with disabilities and mental health problems.

> *For example, the Czech "Green Doors" foundation guides young people experiencing their first psychotic episode through a 1,5 -2 years long vocational rehabilitation program. They social*

[64] Scharle Ágota (2011): A foglalkoztatási rehabilitáció hatékonysága. Kutatási jelentés, Budapest Intézet http://www.budapestinstitute.eu/kutatas/prj/A_foglalkoztatasi_rehabilitacio_hatekonysaga

[65] Sakkeus, L., Medar, M.; Social Integration of Disabled People. Statistics Estonia, Tallinn 2014.

enterprise called Half-Way Café was originally established by a local outpatient centre for young people with mental health problem. The program functions as a supported employment program, guiding users through their recovery process where they can strengthen their own skills and self-esteem and build a strong identity of a skilful employee instead of engaging into a long term psychiatric career. At the end of the rehabilitation process job coaches are helping to find and keep jobs in the community providing a flexible replacement system in case of relapse.

In Hungary, vocational rehabilitation became one of the basic community-based services for people with disabilities and mental health problems. Within the framework of a few years pilot project local NGOs were encouraged to come up with innovative, creative ideas how to increase the employment rate within this target group. Special labour offices were created where social workers and vocational rehabilitation experts were supporting users while they also built up a broad network of employers and potential employees. Later on, these special labour offices got integrated into the official vocational rehabilitation system co-ordinated by regional labour offices that outsourced these services to innovative NGOs and other service providers.

Today the system works based on regular tenders that ends up with 3 years contract with service providers. Services are monitored with strict indicators where service providers need to prove their effectiveness and every 3 years they need to compete with others that continuously forces organizations to introduce innovative solutions to increase their effectiveness.

In Estonia, we recommend to keep the focus of vocational rehabilitation services on solutions targeting integration into the open labour system. Vocational training programmes (Astangu Rehabilitation Centre for example) are very effective with impressive results but we find it problematic that current regulation separate these trainings from general vocational programmes strengthening the segregation and exclusion of disabled people. Within the framework of Work Ability reform we recommend stronger connection between labour offices and innovative service providers acknowledging their expertise and results while also making sure that a co-ordinated and carefully monitored process ensure that always the most effective and most innovative service providers are working in the field.

Motivating and involving employers into the reforms is very important. The current system is still too rigid for companies. A more flexible preferable e-solution might be introduced to allocate resources to business partners. Besides physical improvements new working methods need to be encouraged but in this field we believe more training is needed for both employers and professionals working in labour offices.

User involvement

In modern rehabilitation processes user involvement became very central. Today we can claim that no care and rehabilitation system can provide high quality work without a large level of user involvement. Changing the physical environment, introducing community-based services are important steps on this long journey but without changing the service attitude and the position of service users within the rehabilitation process, no reforms can be successful.

As we already mentioned, different factors together are leading to independent life in the community. A new community-based service structure, training of staff and managers, changing general service attitude are preconditions for a quality care. In order to create person centred solutions in care strong advocacy movement, different understanding of guardianship, greater involvement of service users, supported decision making mechanism and individual financial schemes are needed. These elements

are complementing each other, using only some of them will undermine the expected results of the reforms.

We found in Sweden the strongest example of user involvement and an emphasis on the user perspective in care. According to the Social Services Act municipalities are responsible to promote people's economic and social security and the assistance they provide must be formulated so that it strengthens people's potential to live an independent life. The legislation also guarantees that people will receive the help they need and that they can influence the support and services they receive. To the greatest possible extent, the individual must be granted influence and co-determination over initiatives that are provided.

The Assistance Benefit Act (LASS) regulates that the individual decides for him or herself how the assistance is to be organised. He or she may be an employer and employ one or more assistants, or together with other persons with disabilities may form an association or co-operative that becomes an employer for several assistants, or alternatively may engage a company or organisation for assistance with employer responsibility.

With the aim of achieving increased insight and greater freedom of choice for the individual, the Government has also encouraged the municipalities to develop a system for open comparisons, and has introduced a law that makes it possible for an increased number of practitioners, in competition, to offer their services within social services.

In the United Kingdom, we found very strong emphasis on Recovery oriented solutions that approach is originated in the user movement. The national ImROC[66] programme supports local NHS[67] and independent mental health service providers and their partners to become more 'recovery orientated'.

In Estonia, we found promising examples of user involvement and user initiatives. Recovery model is present in the Estonian mental health system and we also can find very user oriented solutions in the health sector embracing the Finnish Open Dialogue model. The first recovery colleges have been started in Estonia, we found service providers to train and employ peer support workers and DUO Kirjastus is the first user led social enterprise in Estonia in the field of mental health. ~~The most~~ Progressive user oriented approaches are present in the country.

On the other hand, the general attitude of social and health services is still far from a person-centred approach and large level of user involvement. 24 care services in their current forms are not organized in a person-centred way, users have no real choice and only limited control over their care and their life in general. We recommend to incorporate strong references of co-determination to the legislation regulating social services and together with a personal budgeting scheme allowing greater freedom of choice for users and user organizations.

[66] Implementing Recovery through Organizational Change http://www.imroc.org/ (last download 26th of September 2015)
[67] National Health Service

List of references

1. Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)
2. Alleman, J. R. (2002). Online counseling: The internet and mental health treatment. Psychotherapy, 39, 199-209
3. ANED (2009) The Netherlands – ANED country profile http://www.disabilityeurope.net/content/pdf/Netherlands%20ANED%20country%20profile.pdf
4. Applica & CESEP & European Centre (2007) Study of the Compilation of Disability. Statistical Data from the Administrative registers of Members States.
5. 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 26th of September 2015)
6. Bugarszki, Zs.: A szociális szolgáltatások újjászületése Magyarországon. ESÉLY 2004/4 Budapest 2004
7. Bugarszki, Zs., Eszik, O., Szentkatolnay M., Sziklai, I.: Deinstitutionalization and Promoting Community-Based Living in Hungary. ELTE University, 2011
8. Chisholm D, Hallam A (2001). Changes to the hospital-community balance of mental health care: economic evidence from two UK studies. In Brenner H, Boeher W (eds), The Treatment of Schizophrenia—Status and Emerging Trends, Kirkland: Hogrefe & Huber, 210–224.
9. Coid J. (1994). Failures in community care: psychiatry's dilemma. Br Med J 1994; 308,:805-806.
10. Common European Guidelines on the Transition from Institutional to Community Based Care http://deinstitutionalisationguide.eu/ (last download: 26th of September 2015)
11. Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012)
12. Concluding observations on the initial report of the Czech Republic. May 2015.
13. Concluding observations on the initial report of the European Union. September 2015.
14. Craig T, Garety P, Power P et al (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *Br Med J 2004*;329:1067.
15. Department of Health and Social Security 1971). *Hospital Services for the Mentally Ill*. London: HMSO.
16. Department of Health and Social Security (1975). *Better Services for the Mentally Ill*. London: HMSO
17. Department of Health and Social Security (1981). *Care in the Community.* London: HMSO.
18. Department of Health (1989). Modernising the Care Programme Approach: Effective Co-ordination of Mental Health Services. London: HMSO.

19. Department of Health (1990). *The Care Programme Approach for People with a Mental Illness Referred to the Specialist Psychiatric Services.* London: HMSO.

20. Department of Health (2000). *NHS Plan.* London: Department of Health.

21. Department of Health (1999). *National Service Framework for Mental Health: Modern Standards and Service Models.* London: HMSO.

22. Department of Health (2011) No Health Without Mental Health: a cross-government mental health outcomes strategy for people of all ages. London: Department of Health.

23. Developing Community Care – Report of European Social Network. 2011. Brigthon UK. http://www.esn-eu.org/developing-community-care/index.html (last download: 26th of September 2015)

24. Emerson, E., Hatton, Chr., Robertson, J., Roberts, H., Baines, S & Glover, G. (2010).People with Learning Disabilities in England 2010. London: Department of Health. Emerson, E., Hatton, Chr., Robertson, J., Roberts, H., Baines, S & Glover, G. (2011).People with Learning Disabilities in England 2011. London: Department of Health.

25. Evans, J., 2001. Independent Living and Centres for Independent Living as an Alternative to Institution. disability-studies.leeds.ac.uk

26. 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 Esélyegyenlőségéért Közhasznú Non-Profit Kft. Budapest 2015

27. Glover G, Arts G, Babu KS (2006). Crisis resolution/home treatment teams and psychiatric admission rates in England. Br J Psychiatry 2006;189:441-445.

28. Hanzl, V. (2010). Glosy k návrhu tezí zákona o sociálních službách [Proposals for amendment of the act on social services.]. Rezidencˇní pécˇe, 1, 11

29. Health and Personal Social Services for People with Disabilities in The Netherlands. A Contemporary Developments in Disability Services Paper. NDA, 2011. Retrieved October 2015: http://nda.ie/Policy-and-research/Research/Research-publications/Developing-Services-for-People-with-Disabilities/Health-and-Personal-Social-Services-for-People-with-Disabilities-in-The-Netherlands/

30. 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.

31. 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: 26th of September 2015)

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

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

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

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

36. Initial report of Sweden to the UN Monitoring Committee. February 2011.

37. Johnson S, Nolan F, Pilling S, et al (2005). Randomised controlled trial of acute mental health care by a crisis resolution team: the north Islington crisis study. *Br Med J 2005*;331:599.

38. Killaspy, H. (2006). From the asylum to community care: learning from experience. British Medical Bulletin (2006) 79-80 (1): 245-258. First published online: January 23, 2007.

39. Killaspy H, Bebbington P, Blizard R, et al (2006). The REACT study: randomised evaluation of assertive community treatment in north London. *Br Med J 2006*;332:815-820.

40. Knapp, M.; Funk, M.; Curran, C.; Prince, M.; Grigg, M.; McDaid, D. Economic barriers to better mental health practice and policy. Health Policy Plan. 2006 May;21(3):157-70.

41. Lawton-Smith, S., McCulloch, A. (2013). *A brief history of specialist mental health services.* London: Mental Health Foundation.

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

43. 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

44. Macpherson R, Shepherd G, Edwards T. (2004). Supported accommodation for people with severe mental illness: a review. *Adv Psychiatr Treat 2004;*10:180-188.

45. Marshall M, Lockwood A. (1998). Assertive community treatment for people with severe mental disorders (Cochrane review). In the Cochrane Library. (Issue 4).

46. McCrone P, Johnson S, Thornicroft G. (2001). Predicting the costs of community care for individuals with severe mental illness in South London. Schizophr Bull 2001;27:653-660.

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

48. Morris, J., 2004. Independent living and community care: a disempowering framework. Disability & Society, 19(5), pp. 427-442.

49. National action plan on transformation of residential social services http://www.employment.gov.sk/files/legislativa/dokumenty-zoznamy-pod/narodny-plan-deinstitucionalizacie_en.pdf (last download: 26th of September 2015)

50. "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

51. Petri, G.; Kozma, Á.: Mapping Exlcusion. 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: 26th of September 2015)

52. 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/
53. Replies of the Czech Republic to the list of issues. December 2014
54. Replies of the European Union to the list of Issues. June 2015.
55. Resolution of the Government of the Czech Republic of 21 February 2007 No. 127.
56. Sakkeus, L., Medar, M.; Social Integration of Disabled People. Statistics Estonia, Tallinn 2014.
57. Scharle Ágota (2011): A foglalkoztatási rehabilitáció hatékonysága. Kutatási jelentés, Budapest Intézet http://www.budapestinstitute.eu/kutatas/prj/A_foglalkoztatasi_rehabilitacio_hatekonysaga
58. Šiška, J., July Beadl-Brown (2011). Developments in Deinstitutionalization and Community Living in the Czech Republic. Journal of Policy and Practice in Intellectual Disabilities Volume 8 Number 2 pp 125–133.
59. 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.
60. Thornicroft G, Tansella M. (2004). Components of a modern mental health service: a pragmatic balance of community and hospital care. *Br J Psychiatry 2004*;185:283-290.
61. 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.
62. United Nation Convention on the Rights of Persons with Disabilities Article 19 http://www.un.org/disabilities/default.asp?id=279 (last download: 26th of September 2015)
63. Van Weeghel J, van Audenhove C, Colucci M, Garanis-Papadatos T, Liegeois A, McCulloch A, et al. (2005). The components of good community care for people with severe mental illnesses: views of stakeholders in five European countries. Psychiatr Rehabil J 2005;28:274-281.
64. Wilken, J. P.; Hanga, K. (ed) Stories of Recovery and Participation – experiences and challenges. Institute of Social Work Tallinn University. Tallinn 2015
65. Zarb, G. (2004). Independent Living and the Road to Inclusion. 191-206. In: Barnes, C. and Mercer G. (eds). Disability Policy and Practice: Applying the Social. Leeds: The Disability Press, 191-206).