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Deinstitutionalisation and Promoting Community-Based Living in Hungary

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Contents

Background

In 2010, in cooperation with the Soteria Foundation, the Faculty of Social Sciences of the University of Eötvös Loránd (ELTE) released two studies[1] on European Union programmes, and their background, which promote the integration of people with disabilities and people with mental health problems.

The present study is comprised of three sub-studies. In the first study, Zsolt Bugarszki examines the policy developments of the past one year related to deinstitutionalisation. The second sub-study was carried out by István Sziklai and Miklós Szentkatolnay who summarize the results of a survey they had implemented. In this survey, the heads of 10 large institutions and the senior staff of the county governments that maintain these institutions we interviewed, seeking their views with respect to deinstitutionalisation. In the third part of our study, Orsolya Eszik presents the *raison d'être* for deinstitutionalisation in Hungary through the example of two institutions which have made significant steps towards the elaboration of rehabilitation programmes, have been successful in facilitating the residents of institutions to leave the institution and to lay the foundations for an independent living.

Similarly to the studies we published last year, the objective of the present study is to document issues related to deinstitutionalisation. Additionally, with our commitment to deinstitutionalisation, our arguments and thoughts, we wish to make a positive impact on the institutional reforms that we hope are about to start.

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[1] Zsolt Bugarszki, Orsolya Eszik, Ágnes Soltész and Sziklai István (2010), *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*, Budapest, Soteria – ELTE TÁTK, Budapest.

Zsolt Bugarszki, Orsolya Eszik, Ágnes Náray, Ágnes Soltész, Bertold Szekeres, István Sziklai (2010), *One step forward, two steps backwards part2 – Deinstitutionalisation of large institutions and promoting community-based living in Hungary through the use of Structural Funds of the European Union* - ELTE TÁTK, Budapest.

1. The most important developments of the deinstitutionalisation since the change of government in 2010

The change of government which took place following the parliamentary elections in 2010 significantly slowed down the issue of deinstitutionalisation. Due to the nature of election periods, the possibly leaving government does not engage in substantial measures, while the newly elected administration, for a long time, is rather busy establishing its own structure.

The same happened in 2010 in Hungary as well. The earlier deadlines set for deinstitutionalisation expired, the European Union call for applications that was withdrawn due to significant civil society and professional protests was recalled by the National Development Agency which then ordered that a Tender Preparatory Working Group (PEMCS) be set up.[2]

Although the new Working Group successfully ended its activity, in practical terms, new call for applications was never announced, and neither the leaving government nor the National Development Agency made any further steps before the elections to facilitate the process.

In fact, following the elections, for months no information was made available about the new government's plans. The only piece of information in the issue appeared in a newspaper article in the summer of 2010. In it, the newly appointed Deputy Secretary of State responsible for social policy noted that he disagreed with the idea of setting up institutions with the capacity for 12 people in the future.

> *„The Deputy Secretary of the State Secretariat for Social, Family and Youth Issues made a pledge that those individuals who are willing to, and are prepared to, be relocated, will be relocated. Mr. Imre Nyitrai reminded that the Socialist government was supposed to start planning the relocation as far back as in 2007, which would have resulted in announcing the first calls for tenders two years ago; however, „for them this issue was not important". Mr. Imre Nyitrai disagrees with the earlier provision which stipulated that institutions with a capacity for 12 people need to be established.*
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> - *Taking into consideration also the opinion of both maintainers and service providers, we have arrived at the conclusion that, in the case of people with multiple or serious disabilities who*

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[2] From protest up to an agreement, and more, see: http://tasz.hu/betegjog/tiltakozastol-megallapodasig-es-tovabb-az-nfu-esete-totalis-intezmenyekkel-3-resz (last accessed: January 30, 2012)

> *have high nursing care needs, this number is low since the care provided to them involves significant use of public funds."*[3]

Although this statement shall not be considered official information and it was not too detailed either, it still is noticeable that this approach fails to consider the compromise agreement of 2009 concluded following lengthy negotiations, and which was reached between civil society organisations that raised their voice in this issue and professional groups, the sectoral ministry and the National Development Agency.

A spectacular manifestation of the delay which was perceivable in the issue was when, in August 2010, the *Hungarian Disability Caucus* published its shadow report before the government report was released,[4] and made it public in the framework of its own event. It was primarily the government that had a reporting obligation and which, two years after the ratification of the UN Disability Convention, had to report on the completed tasks and the achieved results.

However, this report[5] was not produced until as late as October 2010. In a paradox way, the shadow report produced by civil society organisations preceded it. A comparative analysis about the relationship of the two reports[6] produced by a working group of the *Hilscher Association* reveals that, while the NGOs produced a detailed report of exceptionally high quality and widely publicized it, the government released an official report which, in an itemized way and in a static manner, listed the domestic laws in the field, and which lacked any significant professional and public debate.

For a long time, the government report was very difficult to get access to. In comparison, both the Hungarian and the English versions of the shadow report have been accessible for download from the website of a number of organisations. The government report essentially lists the relevant domestic laws and the services that have been established along those laws. In relation to Article 19 of the Convention which details the fundamental principles of

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[3] „Prison life" of people with disabilities, Weborvos: http://www.weborvos.hu/lapszemle/fogyatekos_emberek_bortonelete/161033/ (last accessed: January 30, 2012)

[4] *Rights of people with disabilities or disability rights*. Hungarian Disability Caucus. http://sinosz.hu/sites/default/files/CRPD_alternative_report_hu_2010.pdf (last accessed: January 30, 2012)

[5] National Report based on Article 35(1) of the Convention on the Rights of Persons with Disabilities. Hungary. Ministry of National Resources, October 15, 2010.

[6] Shadow report and comparative analysis of the National Report, Hungarian Disability Caucus. Hilscher Association, 2011.

independent living and inclusion in the community, the government report lists all available services. However, neither in this chapter, nor in the entire document, any mention is made about deinstitutionalisation as a current policy objective. Hence, the official government report which summarizes the events of the two years after the ratification fails to offer information on deinstitutionalisation of large institutions and on the political intentions with respect to it.

The first comprehensive government briefing which can already be considered official was held in December 2010, in a strongly filtered professional environment of an international meeting in Hotel Astoria in Budapest. The meeting which the government attended with an English language draft document on deinstitutionalisation was organised on the initiative of European Union officials and its invited experts.[7]

This document clearly showed that, contrary to the policy agreements made earlier, the new government will implement deinstitutionalisation in a narrower scope and with a modified content. The programme plan has left out institutions for people with psycho-social disabilities, and, as a result of deinstitutionalisation, it is intended to establish new institutions with a capacity for as many as 50 people. Furthermore, it became clear that a decision was made to set up another Tender Preparatory Working Group in which representatives of the civil society sector were appointed by the government. In practical terms, the draft tender which was elaborated by the Tender Preparatory Working Group that was set up as a result of an agreement made in 2009 fell into oblivion. A new body was set up, and in it, representatives of the civil society sector appointed earlier were not included; the new government - without genuine civil society authorisation - itself appointed representatives of the civil society sector into the body.

With respect to the intentions of the government, while the international experts who took part in the event expressed their satisfaction over the circumstance that the Hungarian government continues to be committed to implementing deinstitutionalisation, they also formulated their cautious but clear criticism. In his presentation, Mr. Jan Pfeiffer, representing the Ad Hoc Expert Group of the European Commission dealing with deinstitutionalisation, made the following recommendations specifically referring to the situation in Hungary:

- The deinstitutionalisation strategy shall cover all target groups in large institutions, including children and people with mental health problems.
- The stated fundamental principles and goals shall be in harmony with Article 19 of the UN Convention.

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[7] The document which was circulated before the meeting is still not accessible publicly; our research team obtained its English language version from one of the international participants.

- Housing related services which support independent living and facilitate the greatest possible integration shall be set up.
- Community-based solutions shall be established also for those people who require non-stop intensive care; establishing/preserving institutions with a capacity for 50 people shall not be pursued.
- Closely related to deinstitutionalisation, there is a need to reorganize the guardianship system which is currently in place in order to enable those affected to make decisions about their own life.
- The legal terms and financial conditions of the community-based services, homes and supported forms of independent living which will replace large institutions shall be secured.
- There is a need to set up a coordinating body to be supervised by the ministry.
- On a county level, it may be necessary to set up working groups which will be responsible for the implementation.
- On both central and local levels, it may be necessary to involve experts in the implementation of deinstitutionalisation.
- In order to map the needs and demands and to facilitate a follow-up of the results of deinstitutionalisation, complex regional strategies need to be elaborated.[8]

Several of the recommendations formulated above have been included in the draft. However, most of them point out the existing inadequacies or dangers.

Among the services that promote independent living, group homes have been in place for more than 10 years, and there are also other community-based services which provide assistance to people's everyday life in their homes. What is clearly a positive development is that "supported living" will be introduced as part of the deinstitutionalisation related plans, as a new type of social service which did not exist earlier. In the framework of this, with state or municipal funding, as small as one-person households can be created within the community up to 6 persons.

Considering this, the comment that even in case of people with the need of intensive care institutions with a capacity for 50 people cannot be considered justified or acceptable, is clearly criticism. Usually, this argument appears in international scientific literature exactly in the opposite correlation: the higher a person's need for care, the more it is needed to

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[8] From a presentation held by Mr. Jan Pfeiffer in Budapest in December 2010.

provide individual solutions.[9] In fact, it is a typical disadvantage of large institutions that they are unable to meet these individual needs. Nevertheless, the common belief that the need for more intensive care can be adequately provided only by large institutions is still stubbornly held. This will be demonstrated also in the later chapters of this study.

The recommendations of the international working group were later confirmed in writing, and at the same time assistance was offered to the Hungarian government in elaborating a concept which is consistent with the UN Disability Convention and the relevant European Union recommendations.

The deinstitutionalisation related ideas outlined by the government in December were later translated into a deinstitutionalisation strategy envisaged for 30 years.

Also at the end of the year 2010, the National Development Agency released for review its Action Plans related to the EU tender programmes for 2011-2013 which create the financial basis for the deinstitutionalisation programme. Within these action plans, from the point of view of deinstitutionalisation, priority is given to programmes under TIOP[10] 3.4.1. and TIOP 3.4.2. Civil society and professional organisations, which made their voices heard earlier as well, expressed their views in relation to the plan in the form of an open letter,[11] and also requested consultations from the senior officials of the Ministry of National Resources and the National Development Agency.

To resolve the visibly growing professional tension, on January 7, 2011 the State Secretariat organised consultations with the civil society and professional organisations which had earlier formulated the open letter. However, the notification about the meeting was circulated among the stakeholder organisations only 12 hours before the event, hence those organisations had no chance to reschedule other activities and thus to develop a common platform.

The majority of the invited organisations did not attend the convened consultation and rejected this form of consultation in another open letter.[12]

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[9] Schwarte, Norbert – Oberste-Ufer, Ralf (1999), *LEWO. Quality of Life in the Living Forms of Adults with Mental Health Problems. Aid to Quality Development*. Budapest, BGGYTF.

[10] Social Infrastructure Operational Programme.

[11] Clear objectives for the use of the 13 billion HUF! The National Development Agency and deinstitutionalisation of large institutions (part 5) http://tasz.hu/betegjog/egyertelmu-celokat-13-milliard-forint-felhasznalasahoz-az-nfu-es-tomegotthonok-kitagolasa-5 (last accessed: January 30, 2012).

[12] „The Ministry of National Resources disregards the written rules of social consultation”, see at: http://tasz.hu/betegjog/nefmi-semmibe-veszi-tarsadalmi-egyeztetes-irott-es-iratlan-szabalyait (last accessed: January 30, 2012)

In the rather acrimonious situation, a sharp exchange of letters started between the staff of the Hungarian Civil Liberties Union and the deputy State Secretary, accusing each other of influencing various organisations and discontinuing the process of deinstitutionalisation.

A letter written by the Ministry of National Resources secretariat responsible for social policy offers more insight into the ministry's ideas related to deinstitutionalisation:

> *„In the summer of 2010, members of the new government responsible for social policy reviewed the situation and decided that, in the future, the government will not authorise construction of new large institutions in this field, and will limit the capacity of nursing institutions to 50 people, while the size of group homes will be limited to 12 people. At the same time, the government accepted the conclusions made by the Hungarian Civil Liberties Union, namely, that, where possible, care shall be provided in their homes, and that the housing issue with relation to people with disabilities shall receive separate support."*[13]

Therefore, there is evidence that in January the ministry still insisted on institutions with a capacity for 50 people despite the circumstance that, during consultations with EU officials and experts, government representatives received critical remarks with respect to this.

About the plans related to deinstitutionalisation the wider public was informed at the beginning of March 2011 when the government issued a short brief about its plans. This brief revealed the following in relation to the expected group home programmes:

> *„As deputy State Secretary Mr. Imre Nyitrai explained, housing related services can be divided into three levels. The first level provides flats integrated in a social and living environment, for 3 to 6 people who need a low level of care and supervision. The second level provides houses for 6-12 people each, while the third level provides residential centres for people in need of intensive care. In addition to the high level of care provision and supervision, residential centres are placed in integrated environments, in buildings with a capacity for maximum 50 people, deputy State Secretary explained. He pointed out that the programme elaborated by the government was drafted in line with the UN and EU requirements."*[14]

One should notice that, in its communication released for the wide public, the government informs the population that its plans related to deinstitutionalisation are in line with UN and

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[13] Letter of the deputy State Secretary of the Ministry of National Resources to Mr. Balázs Dénes, President of Hungarian Civil Liberties Union, see at: http://tasz.hu/files/tasz/imce/2011/nyitrai_imre_levele_11.02.25.pdf (last accessed: January 30, 2012)

[14] „Large institutions need to be replaced with smaller ones", see at: http://www.fidesz.hu/index.php?Cikk=159670 (last accessed: January 30, 2012).

EU requirements. However, the communiqué failed to mention that, in connection with the highlighted specific issues, the visiting experts formulated numerous concerns and recommendations for review.

The draft of the complete deinstitutionalisation strategy was made public in March 2011, and the deadline for submitting opinions was set for April 1, 2011. An email address was provided where stakeholders and others could submit opinions. Contradicting the anomalies of earlier consultations, the ministry sent an exhaustive answer to each opinion. The more than 30 contributions were collected into several detailed studies which were submitted to the Ministry. Subsequently, based on the studies, a summarizing analysis was made, and representatives of the sectoral ministry stated their position with respect to the submitted recommendations in the framework of a one-day event. The event, which was open for any interested parties, expanded into a long debate.

It seems an unusual contradiction that, while the new government systematically disregarded the established consultation mechanism, this specific solution was implemented with such a detail and thoroughness which was unprecedented in the past 20 years in Hungary.

The defect of this consultation was in that the deputy State Secretary who had earlier made it clear that the possibility of establishing institutions with a capacity for 50 people (worded by the Ministry as residential centres) was a fixed part of the concept and in connection with which there is no room for debate, was not present at the event.

The consultation ended in this spirit and, eventually, the draft strategy for deinstitutionalisation was adopted on July 21, 2011, and thus became an official document in the form of a government regulation.[15]

Therefore, between December 2010 and July 2011, progress was made in that the new government’s plans with respect to deinstitutionalisation were made clear. Being aware of the developments in other areas, the fact that the issue of deinstitutionalisation was not removed from the agenda is in itself a positive result, which entails that the EU funds designated for this will continue to be spent on this issue.

At the same time, the professional content of deinstitutionalisation again significantly changed. The consensus which had been reached as a result of lengthy debates and numerous conflicts, with the change of government became null and void. Only after months of delay, it became clear that the new approach again turned the care provision system towards setting up large institutions.

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[15] Government regulation No. 1257/2011. (VII.21.)

Knowing the adopted government regulation, we can state that, although the debate on the deinstitutionalisation strategy went on for half a year, sometimes with conflicts, sometimes on a constructive basis, it did not have any significant impact on the governmental approach. In its most important elements, the official deinstitutionalisation strategy that is planned for 30 years is based on the same ideas which the government outlined first in December 2010.

All this, of course, does not remain without consequences. Due to similar outcomes in other areas, advocacy and civil society organisations expressed an increasingly strong dissatisfaction with respect to the government's consultation policy.

As far back as in September 2010, the Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ) pointed out that a number of events and measures had taken place in Hungary which make it important to convene the legitimate consultation forum, the National Disability Council which the government had neglected for many months.

The issue was still on the agenda in spring of 2011 when several organisations that have been active in the area of disability rights organised a demonstration in front of the building where an EU conference on disability was organised in connection with the Hungarian EU Presidency. Organisations and experts whose opinion differed from the government's position practically were not able to participate in the event.

Parallel to the same conference, Mental Disability Advocacy Centre (MDAC) organised a side event in a building opposite the one in which the conference took place.[16]

The demonstrating organisations formulated an open letter to the Prime Minister in which, among many other measures, they criticised the following:

> *„Although in its campaign FIDESZ-KDNP had referred to the unfair situation of advocacy organisations, the current government does not communicate with the advocacy organisations which represent people with disabilities. It has failed to convene the National Disability Council which is the top level advocacy body representing the interests of people with disability for one year, whereas, based on the law on the rights of people with disabilities, this is the obligation of the decision makers. In the past one year, without consultation, a number of laws have been passed that also dramatically affect people with disabilities."*[17]

Following the adoption of the strategy, in August 2011 a coordinating body responsible for the implementation of deinstitutionalisation was set up. Following its establishment, the

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[16] NGOs discuss human right sin Hungary http://mdac.info/node/707 (last accessed: January 30, 2012).

[17] Open letter to Prime Minister Viktor Orbán. Evaluation of the year by people with disabilities. http://www.weborvos.hu/egeszsegpolitika/nyilt_level_orban_viktor_miniszterelnok/174644/

government again held a press conference on which, according to press releases, the following was stated:

> *„Among those who take part in the work of the National Body that coordinates the deinstitutionalisation of institutional capacity, there are people with disabilities, advocacy organisations which represent them, social background institutions, special education and social institutions of higher education as well as the maintainers of the services.*[18]

In comparison, a few days later, the Hungarian Association for Persons with Intellectual Disability released the following announcement:

> *„Neither affected people with disability, nor organisations that represent people with disability were provided a place in the recently established deinstitutionalisation body. This is how can be summarised what Mr. Imre Nyitrai, deputy State Secretary responsible for social policy announced."*[19]

The above examples well demonstrate that, by the autumn of 2011, communication related to deinstitutionalisation had practically split into two. Although the consultations held in the issue also had encouraging moments, the government overrode the agreement made with its predecessor in 2009, and came up with its own deinstitutionalisation plans which the actors in the field had no chance to influence.

At the time of finishing this study, the European Union tender for deinstitutionalisation was announced, and, among others, due to the above criticism, the coordinating body was expanded to include additional participants. These events will be examined in detail in our next report which will be based on an ongoing monitoring programme.

The implementation of deinstitutionalisation is about to be launched. However, there is no consensus that would involve all stakeholders or compromise which would be essential for the implementation of deinstitutionalisation. While, using various communication tools, the sectoral ministry has been trying to pretend that there is a wide consensus and international acceptance in the issue, it is stuck with its position which it has held from the very beginning.

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[18] A body set up for a more humane placement of people with disabilities who live in institutions. http://www.galamus.hu/index.php?option=com_content&view=article&id=84279%3Atestuelet-alakult-az-intezmenyekben-lako-fogyatekkal-elk-emberibb-elhelyezeseert&catid=76%3Ahazai-vonatkozasu-hirek&Itemid=113 (last accessed: January 30, 2012)

[19] Conciliation of interests without those affected, or, everything about us - without us. http://kulcsprogram.blog.hu/2011/08/16/erdekegyeztetes_az_erintettek_nelkul_avagy_mindent_rolunk_nelkulunk (last accessed: January 30, 2012)

These solutions already fall outside of the range of a (strictly speaking) set of policy tools. In the area of decision making, we can witness unusual solutions also in relation to the field of disability. As experts, we can only reiterate that without a fundamental consensus reached with various policy actors, the process of deinstitutionalisation cannot be successful.

2. Opinions of key experts about the possibility of deinstitutionalisation

Background

Making an analysis of the problems related to the EU co-funded tender which targets the deinstitutionalisation of large institutions, the conclusion of an earlier study we had carried out was that:

> *„The known and unsurprising fact that the major barrier for the elimination of large institutions is their operators and maintainers themselves is also known from international experience. It is not difficult to understand, and, in fact, there is something absurd in it, that what we expect is that a system which has developed a functioning set-up that has been in place for many years now and which has secured a livelihood shall eliminate itself. This is not helped either by the circumstance that all this happens through tenders.*
>
> *Taking the Hungarian circumstances into account, it is further complicated by the circumstance that a whole administrative level, in particular the system of county governments is tightly connected to large residential institutions. With the elimination of such enormous institutions, the county level local self-governments, which have fairly little jurisdiction anyway, would lose an important part of their own legitimacy. While an institution which employs between 150-200 people, or a whole group of such institutions may justify the maintenance of a separate administrative level, 15 homes of the size of a family house in the county would hardly. We do not claim that the maintenance of such institutions is the only task local self-governments have, but we do claim that without it their position would further weaken."*[20]

As part of the present study, we intended to learn more about the deinstitutionalisation of large institutions, primarily from the aspect related to maintainers of institutions. We believe that among the reasons behind the problems related to deinstitutionalisation in Hungary are the lack of professional and political consensus, the lack of assuming the various interests and discussing them openly, as well as the lack of adequate responses.

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[20] Zsolt Bugarszki, Orsolya Eszik, Ágnes Soltész and Sziklai István (2010), *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*, Budapest, Soteria – ELTE TÁTK.

Method

In order to get to know these factors better, we carried out interviews with 10 key stakeholders who have been active in the field of maintaining institutions. When selecting the interviewees, we aimed at identifying, and including in the sample, primarily maintainers of large institutions. Additionally, we also interviewed heads of institutions who were, or are, key players in the future deinstitutionalisation process. Our interviewees were mainly active, opinion-shaping professionals who represent various distinctive opinions.

We are aware that our sample is not representative. At the same time, we believe that these interviews are outstandingly suitable to demonstrate and illustrate those arguments that have been shaped for and against deinstitutionalisation. The general situation in Hungary is probably well demonstrated by the circumstance that the majority of our respondents did not consent to revealing their name.[21] For uniformity reasons, we decided not to reveal any of our interviewees' names and to avoid any and all references which may be used to clearly identify them.

The interviews were carried out in the summer of 2011.[22] As regards methodology, we opted for semi-structured interviewing, which technique we chose because, as a qualitative method, it stands in between the individual in-depth interview and the more quantitative structured interview. The elaborated list of questions contains a few closed or optional questions, but additionally several open questions as well which provide room for the individual thinking and opinion shaping of the respondents. Each respondent was interviewed separately, and one interview lasted between 1-1.5 hours.

Part of our questions focused on our broader topic, namely, the respondents' earlier activities and their „involvement" and tasks related to people with disabilities and people with mental health problems. Then we continued with their experience related to deinstitutionalisation. Finally, the third group of our questions dealt, in more general terms, with deinstitutionalisation and its situation in Hungary.

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[21] In the course of examining this issue, it was for the second time that we had come across this phenomenon. The fact that, narrowly defined, professional issues of a public task that is fundamentally financed from public funds are decided in a secretive environment is thought-provoking. In the research which we carried out last year, the (typically) civil servants who were, as a rule, responsible for public matters and who took part in the planning and implementation of EU tenders did not agree to disclose their names when they shared their opinion and professional views, and the same happened in this study with resepect to persons responsible for the maintenance and operation of the institutions.

[22] We hereby gratefully thank our interviewees for undertaking the interviews. The interviews were carried out by Miklós Szentkatolnay.

Respondents' professional background

Based on the recorded interviews (10), the interviewed heads of institutions and heads of their maintainers have been working in the social field for the past 20-30 years, primarily in institutions that provide care for people with disabilities or in places where also people with disability lived. From among the types of institutions stand out large institutions which provide long-term residential housing. Only very few respondents had a professional experience of less than 10 years in the field of institutions that provide care for people with disabilities.

The current heads of institutions have typically gone through one of the two professional paths: they either have been in this senior position from the beginning, or have gone through the professional hierarchy from subordinate positions (care giver, teacher), through a middle manager position (e.g. professional leader) to the position of the head of institution. Representatives of maintainers (in our sample, typically from county self-government offices) in general have not worked in the field, or in institutions, or directly with the target group; generally they started their career as officials and have stayed in this role. Essentially, they know the institutions only from this maintainer perspective.

As an illustration, below see the career of the department head of an institution for people with disabilities. This career, at the same time, describes the changes the system has gone through:

> *I have been dealing with people with disabilities since 1986. At the beginning, I worked as an unqualified care giver. Our institution has been in place since 1970. It is located outside of the settlement. The goal here was explicitly to place people with disability and people with mental health problems isolated from the population of the settlement. At the beginning of the 1980s, a separation of profiles took place by which care provided to people with disabilities and care provided to people with mental health problems were set apart. What is currently called social institutions used to be health care institutions. Professionals with a degree in special education carried out the professional and development work in the institutions, but the supply was insufficient. I went through the entire hierarchy. I started with social administration, then was engaged in writing proposals, later I became a professional leader, and finally the head of an institution.*
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> *At that time, as a care giver, I had to find out what I needed to do mostly myself. It was an important step when an opportunity came to implement meaningful employment, and the notions of protected employment and social employment were introduced.*
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> *At the beginning of the 1990s, the approach that large institutions shall be gradually replaced with a system of care provision in which individual needs are taken into*

> *account emerged. Avoiding excessive care became an explicit goal. I believe that by now the profession has already embraced the approach that a person who receives care is not just a disabled person.*
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> *What is important is that there have been professionals around who one could look up to, who provided professional guidance and who one could follow in developing their professional sense of vocation. This determined the attitude to work and offered new challenges. As a caregiver, I had to know the patients' whole life, their files, family connections. The work with the people in these institutions also involved a lot of personal conversation. Earlier, the daily tasks were not determined by the personnel, but situations that required solution simply „occurred'. These days, there are requirements which say how people in the institutions shall be treated. There is a development plan and it is obligatory to maintain family connections. My personal professional development has always been important for me: my initial education was in the field of social work, then I became a so-called mental health professional, then I passed the professional exam and received the social manager degree as well.*

The interviewees frequently say the following when they speak about deinstitutionalisation in general terms:

> *„Within the profession, there is a view that for a part of the patients deinstitutionalisation is not a solution, and it is not feasible."*

It can be considered as typical that respondents speak about deinstitutionalisation referring to a general view rather than shape their own opinion, or when they do shape their own opinion, they do it very cautiously.

> *„To what extent society is open to having people with disabilities live among other people - is a key question. I clearly do not reject the deinstitutionalisation programme, professionally I cannot say no to it. I have both positive and personal experience, but I believe that there is a group of individuals who do need institutional care," – says a head of a county level institution.*

These two features suggest that we face a fairly rigid system that is incapable of, or is difficult to persuade for, a shift or change when we touch this segment of the social field. It is in these circumstances that the deinstitutionalisation programme wishes to approach the institutional world. This, at the same time, projects the risks and difficulties which this complete endeavour entails.

Those who work in this profession admit that, since the total institutional system of the 1980s, until the service providing system that is in place today, the policy has made a long way full of changes. Currently, the care provision system operates in more up-to-date conditions and within a much better regulated framework than before the transition of

1989-1990. It may seem surprising, but some consider large institutions to be a stiff and impersonal care system exactly due to its regulated nature.

The professional staff of these institutions is in an extremely difficult situation: they feel that there is a need for change, but they are afraid of loosing their job, the established routine, and they feel uneasy about their future. This ambivalence is also typical of their maintainers who, due to the uncertainty that arises because of the changing legal environment, are facing difficulty in finding their place in the deinstitutionalisation programme.

An opinion which was shared by one of our respondents, a man in a senior position who has been working in a home for people with disabilities for more than 30 years, well demonstrates this ambivalence, the cautious but nearly always present concerns:

> *„With respect to deinstitutionalisation, members of the professional staff have questions (not doubts, questions) related to what will happen with the patients, those who are incapable of independent living, since there are people with disabilities who, for instance, are unable to comprehend the notion of time. The forms of housing for lower number of patients do not provide the variety and the dynamics; they always see the same faces, while in an institution this is different - faces change in a dynamic way since patients come and go. Due to this circumstance, patients in large institutions can maintain contacts with people in a better way. We shall not swing to the other extreme: those who cannot, shall not leave the institutions."*

Importantly, the need for constancy as the interest of those affected is frequently emphasised.

> *„At the same time, there is a great need for alternative group home solutions, in particular in case of people with disabilities who require a lower level of care."*
>
> *„It is also good for those who live in group homes that they can go back and visit the institution to maintain their social relations."*

This dichotomy is constantly present: let there also be the new care system (!), but the old one shall also remain! The idea of deinstitutionalisation from this perspective would most likely be accepted with undivided success among the professionals who work in institutions if it did not result in the removal of the present places and institutions, but would become only as a complementary, parallel, alternative form of care provision.

The same is reflected in another interview made with a head of a church-maintained institution: with respect to deinstitutionalisation, professionally, he has a dual feeling – concretely he cannot say that he agrees with it, but neither that he disagrees with it.

> *„Each person with a disability is different, and the process of making society more tolerant is very much in its infancy. It may be possible that, indeed, a strategy needs*

> *to be in place for 30 years. In case of a person with a disability who has lived in an institutions since their babyhood, it requires a great effort and high costs to reach a level that would secure relatively normal living conditions in a family house," – he stated.*

According to the new Local Government Act, the maintainer of institutions in the future will be the state itself (the central government). This fact in itself may become an obstacle to the implementation of a programme financed by a European Union fund that specifically supports deinstitutionalisation (that is, the implementation of the TIOP 3.4.1 „A" tender scheme). According to the current plans, similarly to the earlier tender documentation plans of the same scheme, only the maintainer can apply for the tender, except in cases where the maintainer is the state. We believe that this possibility is a serious obstructive factor in the implementation of deinstitutionalisation.

> *„Those institutions that are in the poorest condition are not interested in applying for deinstitutionalisation (the TIOP 3.2.1 A tender). What is most important for the personnel working in them is to retain their jobs, therefore, it is the preservation of the existing system that is in their interest",* – summarizes one of our respondents.

The head of another institution located near the capital city which was established among the first ones, being personally involved, stated firmly:

> *„In the course of deinstitutionalisation no tender should be announced, and the demolition of the system should start by identifying those institutions that are in the worst condition."*

However, the respondent was not aware of the professional programme that will be implemented in the framework of deinstitutionalisation. In his view:

> *„The investment shall in any case be preceded by a preparatory professional programme in the framework of which the patients who live in the institution, their relatives and the personnel would be prepared. Then there is a need for a technical team which would understand why there is a need to create and construct the type of building that experts have visualized. This responsible technical team has to be incorruptible. There is a need for a team, or teams, which would be capable of elaborating individual programmes, because without these, deinstitutionalisation will be a failure and a lot of money will have been wasted."*

Although in Hungary conscious deinstitutionalisation has not taken place yet, and no institution has been closed as a result of it, nearly all professionals who we interviewed stated that they had some sort of personal experience in the issue of deinstitutionalisation. Most of them had participated in a process in which people with disabilities were relocated from large to smaller institutions, most frequently to smaller institutions that provide a group home-like environment.

Opinions related to deinstitutionalisation

On the professional level, all of our respondents agreed with the idea of deinstitutionalisation. How exactly they understand deinstitutionalisation and how much they know about it varies a lot. Everyone agreed, without exception, that deinstitutionalisation of institutions needs to be started, but how exactly, in what steps, they had very vague ideas and little, if any, experience. The difference in opinions was even larger when they were asked about the post-deinstitutionalisation service provision structure.

They unanimously agreed that in certain cases, generally in the case of people with mild intellectual disabilities, placement in group homes can be successful, and that it can even become a springboard to starting an independent living. However, only really few professionals among the heads of institutions and their maintainers think that letting patients become 100 percent independent is a solution. Nearly all our respondents would maintain the possibility of a life-long support, in one form or another, in a loose scheme or a tight one.

As regards people with multiple disabilities, it seems even clearer that the way they are treated is inadequate, and that its perspective of resulting in independent living seems barely feasible. In this case, the position of the professionals is clear: they need non-stop supervision and the professionals can hardly imagine that such people could live in smaller institutions or service units, or that they could ever live relatively independently. They believe that care for these people can be provided (cost)efficiently in large institutions, by maintaining a massive personnel.

An informative and very frequent institutional approach is one that generally agrees with deinstitutionalisation, but not with respect to the given institution where they consider deinstitutionalisation impossible.

According to the head of an institution with a capacity for 170 patients,

> "…from among the current patients, I can imagine at most eight patients who could be placed in a different environment and start independent living."

An opposing view was formulated crudely by one of our interviewees (founder, and, since 1980, head of a foundation which provides housing and employment):

> *"Those who work in institutions, subconsciously, do not consider the residents as humans. If they did, then apparently there would be no personnel in these institutions. Somehow this is the culture of residential institutions."*

Knowledge of the deinstitutionalisation strategy adopted by the government was fairly superficial among all respondents. It looks that the strategy's efforts and real course have not yet made their way to the future implementers, to the minds of those working on the various levels of the care provision system.

None of the professionals have indicated which part of the strategy is good or bad, where should changes be made, only some information of general nature was selectively picked out from the document. We believe that this phenomenon may have a number of reasons: either they had not been involved in the elaboration of the strategy, or if they had, then they themselves were not sufficiently committed to thoroughly reviewing it and providing real recommendations based on practical experience. It is also possible that it is simply the usual, acquired inertia mechanism that was behind it, and they thought that things would work out and they would adapt to them, or not. However strange it may seem, this type of (survival) strategy has several grounds. In the past 15 years, a typical feature of Act No. 3 of 1993 has been that the law and its relevant provisions have kept changing (at least once yearly), while only very little attention has been dedicated to its implementation and coherent implementation. Thus, in several cases, those were implemented in a way that was either entirely different from the original intention of the legislative body, or were implemented only in a fragmented or dissimilar way. At the same time, the social care system has in the course of the years learnt to adapt to, take seriously, or, conversely, how to ignore the ever changing regulations.

These reasons are based on our own assumptions; however, the lack of knowledge that can be concluded from the interviews we made certainly draws the attention to the circumstance that the creators of the deinstitutionalisation strategy have/should have quite a lot of work with it in the area of communication and motivation. Furthermore, there is a need for a more active, than today, involvement and orientation of the institutions that are directly affected by the implementation of the deinstitutionalisation strategy. No matter how well-intentioned the strategy is, if those affected show reluctance, do not understand it, its implementation can very easily go wrong, or fail.

An exceptional counter-example was provided by one of our respondents who is the head of one of those maintainers that are responsible for the highest number of institutions. In his view, even the deinstitutionalisation programme is not promising enough in the long run:

> *"With respect to the deinstitutionalisation programme, what I have been missing for a long time beside group homes is that people with disabilities should have the opportunity to move to their own, or rented homes where they could live their own lives in the form of supported living. International examples similarly show that there is a need for flat-homes rather than group homes. There are owners of flats from whom those flats could be rented, where it could be a requirement that they should be barrier-free, easily accessible by public transport, etc. Thus, maintainers would not*

> *have the responsibility to construct, operate and maintain these housing units, but only to control the operation and provide the criteria to the owner how things should be."*

Nowadays, the planning of the deinstitutionalisation programme in Hungary does not always happen in a visible, easily accessible way.[23] The preparation of the strategy involved a long consultation process in which the governmental working group that had created the strategy received feedback. Based on the feedback, quite many of these comments and recommendations – provided that they were found to be professionally acceptable, and unless they did not contradict the previously set ministerial principles – then were incorporated in the strategy. However, these adjustments pertained merely to details, since the really decisive aspects of the deinstitutionalisation strategy had been set on ministerial levels which did not represent themselves on the consultations.

It was not the first time that such a strategy had been used whereby top level officials set the major principles in advance, then, under the cover of consultations, officials who work on levels lower than those at which the real decision making took place in the ministerial hierarchy, organise consultations which eventually cannot influence the main principles set above. This mechanism raises the question of whether such professional consultations can be taken seriously at all. Although there indeed was a thoroughly prepared, booked down event called professional consultations, there was no meaningful dialogue on the important key issues. Thus, the expected outcomes of the consultations were limited exclusively to details.

A further problem was that the proposal makers failed to cover the complete professional spectrum, let alone the direct target group (that is, people with disabilities and people with mental health problems). In case of a reform of this calibre, it would be reasonable to launch a consultation process that is much more intensive and thorough, compared to the usual consultation channels.

At the same time, it is not necessarily only the team which had elaborated the strategy that can be blamed for the difficulties around the consultations, since those who did not comment on it and failed to make recommendations, later have less grounds for criticising the deficiencies to which they could have submitted their recommendations.

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[23] There was a possibility to comment on the strategy via the Internet (on this, see e.g. the website of a methodological institution: http://www.cssk.hu/modszertani_informaciok/modszertani_hirek/2011-03-21/kitagolasi_strategia_.html). We are not aware of an easy-to-read version for people with intellectual disabilities.

The opinions about the professional merits of the developments[24] related to deinstitutionalisation are also mixed. Since only a few respondents had specific ideas about what and how should be done, it is difficult to reach conclusions. What is certain is that those who do have sound plans, those plans are, on average, entirely different from what others and policy decision makers think about deinstitutionalisation.

As one of our respondents who has significant professional experience and is the head of a rehabilitation centre in the Budapest agglomeration said:

> *"In general, there is a will to deinstitutionalise, but this is going to be an immense task, and it is doubtful whether 30 years will be enough for it. There is an urgent need for it, we see this too that people with disabilities also demonstrate progress in development, and they have the right to live in better conditions. What the economic environment will make possible is uncertain. Especially given that the technical literature and politics point out that people with disabilities should live on their own resources, while day by day they experience that these resources are pulled out from under them. Not only it is difficult to get access to disability pension, but it is becoming ever more difficult to get a job, thus an income."*

Obstacles to deinstitutionalisation

It is most interesting to see how the respondents view the issue of support provided to the social field with respect to deinstitutionalisation. While nearly in all cases they state how good it is and how needed it is, at the same time many convey the idea of sustaining the current system, or render it likely in their statements. They also refer to the profession claiming that it maintains this position, or say that the profession generally represents this view. There was a respondent who openly stated that it is not in the interest of large institutions to implement deinstitutionalisation, therefore, they will not support it or urge it, whatever they say.

> *"Those who are involved in the practical preparation and implementation of deinstitutionalisation see the situation and the pitfalls better. But there are things which will be impossible to resolve. Those who know only the theoretical part and believe that it is good, that it needs to be implemented, they get carried away, and in reality they don't know what it is all about. There is a controversy between those who represent civil organisations and those who represent the state, and those who have been in this profession for a long time. Those who have been involved in this system*

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[24] The developments in the area of deinstitutionalisation and the problems related to them were discussed in one of our earlier research studies. On this, see *Bugarszki et al* (2010).

> *for a very long time become moss-grown, they are the ones who believe that the current institutional system is the good one."* – states sharply the leader of a rehabilitation institution.

Opinions, as a rule, refer to the public and the professional opinion, while personal views and clear-cut statements are rare. Respondents prefer to stay on the soil of general perception:

> *"No doubt, there are opponents of deinstitutionalisation, those who do not see their role in this process, and out of fear believe that this is bad for them,"* – according to one of our interviewees.
>
> *"Professionally, I cannot imagine that, say, in 10 years' time, from the current body of patients everyone would be living in a different housing scheme. In principle, it is not impossible, but looking at it realistically, there is little chance for this, and the "how" is also doubtful,"* – said another respondent.

The most important of the key elements in the implementation of deinstitutionalisation is the issue of financing. The stakeholders do not know how the new system is going to work, and what will be its financial basis, which generates tremendous uncertainty and fear.

> *"One impeding factor in the issue of deinstitutionalisation is that there are insufficient funds for the development. There have been no tenders in the past years which would have facilitated this process. Last time it was in 2003 that a development related to deinstitutionalisation took place. It was then that the group homes were constructed on the territory of our institution. In 2006, a call for applications was announced for employment, but otherwise only for accessibility, renovation and patching up,"* – said a professional, head of an innovative institution, with several decades of experience.

Another expert, reinforcing this, shared the following:

> *"The new structure will surely cost more. Money is clearly the obstacle for deinstitutionalisation, but also human resources are an obstacle in this process. Just in our own institution, 3 times 50 people would need to be placed in home centres, because they need care which cannot be provided in group homes."*

The head of professional division of one of the local governments which maintains the largest number of beds, in possession of specific calculations, said the following:

> *"According to our calculations, in order for an institution not to be loss-making, it has to have the capacity for 120 patients. It completely contradicts the idea that, in accordance with the deinstitutionalisation strategy, group homes with capacity for at most 50 patients can be established."*

Another important factor is the provision of proper professional and methodological support for all stakeholders (that is, maintainers, management, personnel and the patients), because they will be unable to implement deinstitutionalisation on their own.

> *"I cannot believe that patients can live a fully independent life in group homes. Group homes require qualified personnel which we currently do not have. So far, in a concentrated area, even in cases of manpower shortage, problems have been solved with rearrangement and overlapping techniques. If one day the patients will be scattered around several places and settlements, these problems will not be possible to resolve,"* – formulated the head of a nursing care institution.

As a good answer to suggestions of this type, we quote here a response given by a senior official of one of the largest local governments responsible for maintenance of institutions:

> *"Institutions cannot implement the deinstitutionalisation programme on their own. There is a need for a "civil" organisation that would coordinate this activity, cooperate with professional organisations, with the local government, and which would promote the community-based approach."*

Another respondent pointed to a very important professional aspect:

> *"A group home, too, can function very badly. It is a serious fear that, in case of lack of professionalism, this will happen. It is less likely to happen in an institution, because if something happens, it will soon be noticed, but who will see what happens in a group home?"*

Perhaps not surprisingly, what is emphasised virtually in all interviews is the issue of the "receiving environment", the preparation of, and making more tolerant, the local and wider society. Provision of open and clear information and awareness raising seem to be important for successful deinstitutionalisation.

> *"It is a fear rooted in the lack of information and ignorance that motivate the opponents not to integrate people with disabilities into society. (…) It was a positive experience when, as part of the deinstitutionalisation programme, the neighbours were brought together with people with disabilities to talk, establish relationships, and as a result of this, the neighbours did not object to the establishment of a group home in the neighbourhood."* – said the head of a successful group home maintained by a county government.

The absence of key elements is, at the same time, the depositary of the obstacles and unsuccessful deinstitutionalisation! If the resources are insufficient, the implementation is doubtful. If the heads of institutions, the personnel, the patients, their relatives, the guardians, as well as the maintainers are not interested in the implementation, will not receive professional support, then, involuntarily or intentionally, they will obstruct the completion of the entire deinstitutionalisation mechanism. If society is unprepared for what it shall expect, and if citizens are unable to integrate people with disabilities in their environment, their neighbourhood, their everyday life, then the programme is destined for failure.

The overall strategy envisages a 30-year implementation period (2011-2041). It is during this period that all the places that are currently occupied by thousands of people with disabilities in residential institutions will need to be deinstitutionalised. At the same time, the first steps are extremely important as they decide the credibility and success of the entire programme: to change the lives of the first 1,500 people with disabilities will take an enormous effort, because the resistance – not necessarily conscious – will be significant and huge. Let us not forget that, under the current regulation, by the end of 2013, in principle, the placement of the first 1,500 people with disabilities in different housing schemes shall be completed, just as the creation and maintenance of the necessary services, that is: the institutions in which they are currently receiving care will need to have been deinstitutionalised and entirely reorganised. All this is especially important because this is the first step which will lay the foundation (in one way or another) for the future developments carried out in this direction, will provide ammunition for the implementation of the future national and European Union funds, and the utilisation of further development funds in this area.

3. Two case studies

Our research team set the task of tracking down any positive examples which could provide hope that deinstitutionalisation in Hungary is not an evil thought. There are institutions which cope with internal and external obstacles, and even under the current circumstances they have been able to set of on the road to implementing independent living as a realistic goal for their residents.

Two locations, a “louder” and a “quieter” were selected to present the case studies. The “louder” example is the story of Derekegyház where, at the very end of the 1990s, an idea matured in the heads of the management of the institution. They decided to create a group home for part of the residents of the large institution (located in a castle) which was situated near the village. We will see that having the idea accepted did not go easily: the first deinstitutionalisation was accompanied by a local referendum and a media campaign. 12 years have passed since then, and today as many as three group homes operate in the settlement, the local community has clearly accepted the people with disabilities who live in the village, and there are even supportive voices!

The “quieter” example was identified near Tatabánya, in Síkvölgy. Here, in the past 10 years, the institution has implemented its deinstitutionalisation rehabilitation programme in three steps. From the classical large institution, the patients can move into the “garden group home” situated in the courtyard, and from there they can then move on to Vértesszőlő, a settlement 20 km away where they can start a much more independent living. For many, even from here, there is a further opportunity to move on to rented flats where they can realise real integration that is independent from the care provision system. In Síkvölgy, the process was quieter: there was no loud resistance among the local population, and there were no reports at that time about neighbours who were indignant about the project.

As a basis, we used the interviews made by students of the University of ELTE who visited Derekegyház in 2009, and also we processed the news reports and relevant communication in relation to the institution that caused much stir at the end of the 1990s. We visited the Síkvölgy site in June 2011 when we made an interview with the head of the institution and its personnel, and we also had an opportunity to speak to a few patients as well.

In both places, we were in the first place looking for the answer to the question of how deinstitutionalisation took place in the past years in those locations where it was made possible due to the progressive thinking of the institution’s management, or due to the favourable tender conditions. In none of the cases can we talk about real deinstitutionalisation in the course of which the entire institution is eliminated. In the examples that we described it was rather that, in addition to the existing and remaining institutions, new models were created which then in many respects served a surprisingly positive result.

In what follows, we would like to present a kind of a best practice collection, naturally, highlighting the most difficult points that require the most attention.

Derekegyház

The village of Derekegyház is situated between Szentes and Hódmezővásárhely in the Csongrád county, Hungary. Its population is 1,800 people. In the middle of the village is the former Károlyi castle in which, since 1949, an institution that provides care for people with moderate disabilities has been in place. The institution does not exist independently, it is part of the United Social Institution that has been blended with the mental health institution in Szentes and the residential home for the elderly in Nagymágocs. In 1999, the first group home was launched in the framework of the institution.

The relocation of the first 10 patients into the group home was not smooth. On their own initiative, the villagers held a referendum on which the majority rejected the initiative that meant to facilitate the independent living of the patients. Mrs. Márton Dávid, the head of the institution, told us that, despite this, the relocation took place since the result of the referendum was not more than an opinion expressed by the local population. As an institution maintained by the county government, the referendum did not obligate them. A court decision was also made in the issue, which well demonstrates the aggravation of the situation in the village. Despite the initially not too encouraging attitude, today there are three group homes in the village and 34 patients live in them.

In 1999, the group home in Derekegyház was the first in the county. At the same time, there had already existed well-established group homes throughout the country. In the opinion of many, one of the reasons for the indignation of the local population was the lack of information: the villagers knew almost nothing about group homes, they were full of prejudice, and neither the media nor the institution raised the awareness about the initiative, while it was needed indeed. The professionals themselves learnt about the initiative on trainings, at conferences or on other professional trips, then they visited functioning group homes. But these examples of best practice and reassuring methodologies remained entirely, or largely, undisclosed to the population of the village.

> *"There is a lot we do not know about the background, why it happened like that (…) When it took place, the villagers did not even know about it. At that time I was*

> *writing my thesis on a similar topic, and I made a few interviews in the village. Then there wasn't a single person who had heard that there already were such group homes in the country. Therefore, what one could see on television was not enough. Should they have seen that, say, in the Transdanubian region or in the Budapest area there were people with disabilities who lived in such homes, the situation may not have gone that far. Besides, I do not know for sure, but there may have been a personal conflict between the home and the doctor, that's what the newspapers wrote at that time. I do not know if that was true or not.*
>
> *Then the loud media coverage quickly died down. It was interesting only for a short while; even the TV broadcast opinions like "we'll see then in a year or two how it will work out". They haven't come back since then, nothing. (…) So, what the media reports on is the scandal part of the story, although it could have presented those group homes which had been well-established in the previous years. For the whole country to learn about those. That's what I think. Then more people would have heard about them."* (Mrs. Márton Dávid, head of institution)

The issue at that time caused much stir on the national level; a separate topic was launched on an Internet forum to discuss the issue. It had the following introductory note:

> *"With a large majority, the population of the village of Derekegyház voted against when deciding on whether ten young people with mental health problems who until now have lived in an institution can move into a family house redesigned for them. In the Csongrád county settlement with a population of 2,000 people, a referendum was held as a result of a local initiative, and from the 737 voters 655 said "no" to the attempt of a handful of people with mental health problems to start an independent living.*
>
> *Despite this, already on Saturday, majority of the young people moved into their new home. According to the court decision, the local population of Derekegyház did have the right to hold the referendum, but for the local government which maintains the group home and which has caused much stir with the initiative, its outcome has no legal obligation whatsoever, told Mrs. Lajkó Valéria Hegedűs, secretary of the Csongrád County Advocacy Association for People with Disability to the* Krónika*, a radio news programme. She fears that the campaign against people with mental health problems in the village will continue. On Sunday, the young people were waiting for the voters with flowers, but nobody accepted those from them. The villagers mocked them and called them fools."* (a quote from a user named "dexter", taken from the Netlap report published in 1999 on an Internet forum which specifically dealt with the Derekegyház issue)

Fairly soon, further comments quoted below appeared:

> *"Because of my occupation, I had to travel to Derekegyház to sniff around and see what the reality in this issue was. Briefly: there is a castle in the middle of the village. Around 150 people with serious mental health problems have been treated here since time immemorial. The head of the institution and a ready-to-help foundation decided to buy a house where they would move some of those patient who are in a relatively good condition, so that, with the assistance of a couple of educators, they would be able to start a more independent life. Naturally, at 8 in the morning they would go back to the castle for treatment, for day-care, activities, etc. Then at 5 in the afternoon they would go home and live their lives, supervised by social workers. This is the story briefly.*
>
> *But a great many questions arose in the minds of the villagers when they heard about it.*
>
> *"If they are not so ill, why do they need to receive treatment? Or if they are ill indeed, then why don't they spend all the time among the nurses, in the castle which was designed for this purpose (where supervision, medical and other care are fully guaranteed!). If they do have to visit the institution, then, from the point of view of recovery, what point is there in independent living (they are unable to live independently, they require nursing personnel, what's more, in several shifts…)."*
>
> *"If they are in such a good, cured condition, why doesn't their family take them home? If they are ill indeed, and only the degree of illness is milder, does it make sense splitting the special personnel working in the castle in the anyway overburdened evening hours?"*
>
> *To conclude, thousands of questions were asked before the referendum yesterday – expressing positions for and against. The result is known. However, the general public knows the facts only superficially and cannot understand the villagers' concerns on the basis of a short report. There are thousands of things that locals fear from, e.g. that, in the evening hours, the people with disabilities will get lost on their way home, will be hit by a car, etc.*
>
> *I spoke with two sisters, they worked as nurses in the institution for 20 years. Even with malice one cannot say that they did not like the people with disabilities, because even during the conversation they kept crying when they remembered the sad fates of many people. Referring to the so many years of experience, they expressed their belief that everything should stay as it is, since in the institution they can receive all the*

> *assistance they may need. EVEN LOVE! But nobody has explained what will happen if, after the relocation, it turns out that the selected patients are not fit for the independent living.*
> An answer which seemed suitable came from a local teacher:
>
> *An Ltd. needs to be established to provide care for the selected patients who are starting an independent living. The patients need to be taken back to the institution saying that they indeed are not fit for an independent living. After this, the building can be used for any purpose, for instance, could be used as a private kindergarten in the scope of activities…*
>
> *Otherwise, the story began to unfold last September, only that the issue got to a referendum just now. Already then, I modestly took the effort to explore the issue in detail, publicly. At that time my personal opinion could not be voiced as my task was to report in a fair manner. Now that I can share my opinion on the issue, I say: it is better if the patients stay in the secure institution and the care provided to them needs to be raised to a higher level because then the chances for recovery will be better. Because if we truly love these lovable people who are tormented by cruel fates, then we shall help them with our hearts, professional knowledge, medicine and love, and not with formalities.*
>
> *Let's not want to force them in a world that they are unable to value, not even if it seems attractive for a healthy person."* (a user named "bcsr" on an Internet forum which dealt specifically with the Derekegyház issue in 1999)

The above quotes reflect the attitude in this issue of both the personnel that work in large institutions, and the typical attitude of the population. Even though the professionals have many years of experience in providing care to people with disabilities, still their experience is one-dimensional. They come across people with disabilities only in one single space – in the closed institutions. Their experience and professional knowledge is limited to this large institutional space, and from this perspective they are people who are unfit for independent living, who need permanent protection and care. For them, despite decades of experience, deinstitutionalisation and reform of the care provision system is not an internal recognition, but comes from above, from their better informed management, or from outside as criticism coming from advocacy and professional organisations. We will see signs of this also through the example of the Síkvölgy institution.

Similarly striking for professionals who are knowledgeable in the topic is how opinions of non-professionals can go in the wrong direction. The commenting person who apparently works as a journalist and who in the forum considers herself quite well-informed, keeps writing about ill people and sees disability as an illness which needs treatment. Seemingly, it is the medical paradigm of disability that became entrenched in the minds of the local population, and within this paradigm the ill people should stay in hospitals and not in family houses. This judgement is so solid that the commenter raises the question: if these people are not (so) ill, then why do they need the institutions at all?

One can see well that when the management of an institution decides to deinstitutionalise, it has to tackle both the inner resistance and the lack of comprehension outside which, as we saw in Derekegyház, can easily lead to a hysterical rejection.

Nevertheless, there were a few commenters whose approach was apparently not based on this paradigm. Not surprisingly for us, they can fairly precisely predict the future developments in this issue.

> *"I am convinced that, in a few years' time, uncle Steve will say something similar: "Oh yes, we are very afraid of these insane people. Of course, the ten people who are here are nice, decent fellows. Józsika, the Mongol, mows the lawn every week for 100 forints, and they have never caused any trouble." Unfortunately, it is these mass institutions that have disaccustomed the Hungarian society from even the sight of people with disabilities, and it will be difficult to get accustomed to it, but in a developing democracy maybe those who are less capable of comprehending it also may have human rights, just because they are humans."* (a user named "Tsy" on an Internet forum which dealt specifically with the Derekegyház issue in 1999)
>
> (…)
>
> *"But what exactly does it mean that they cannot take care of themselves? To what extent shall it be understood? 5-year olds are also unable to take care of themselves, so shall we put them behind bars?! Believe me that if, say, just because they cannot decide on their own what kind of clothes to put on, they should not be kept in quarantine. Why can't they live in an environment that is more intimate than that of the institution? This may really help their condition. Those who are chosen for such a relocation are surely capable of recognising the difference."* (a user named "rahell" on an Internet forum which dealt specifically with the Derekegyház issue in 1999)

The above quotations similarly well illustrate how scarce was accurate, precise and professional information about the group home that was planned to be established, information that is easily understandable also for the community.

The public judgment held by the population is close to that of the medicine-based approach within the care provision system in children’s homes in the 70s and 80s which only very slowly gave in its approach to be replaced by a more up-to-date and integrated one.

Thus, initially there was a huge resistance on the part of the local community against the process which was launched despite the results of the local referendum. The first months were very difficult. Every day, on a regular basis, the ten residents went to the large institution for their day-time activities. A few months later, due to the patience and perseverance of the personnel of the group home, the tension subsided. This is how the head of the institution recalls that period:

> *“… Then only ten residents lived out there, the first house was on its own. Every day, we went here and there; in the morning we escorted them to the institution, in the afternoon back home. … In the village, people made remarks, and everything. But we overcame this. With the residents, in their home, we discussed what exactly happened in the street. Also that it did not matter who we meet, we shall great everyone, because they live here in the village, and we always meet them. So we discussed such things. When the first couple of months passed, we could see that the situation will improve, and later, even those who earlier had not greeted the residents and even turned their head away, started to say hello. So, slowly, but surely, this issue was resolved.*
>
> *After that, when the second and the third group home was launched, then there was nothing. It was already the fourth year, because the next group homes were completed in 1999, then in 2003. Then there were no protests on the part of the villagers at all. The neighbours who lived nearby, in the beginning they would come. Curiosity attracted people, they came to see what happened after the residents came home, to see what they were doing, how they lived. Then, as neighbours, we received them well. The residents learnt to make coffee. They poured it out, invited the neighbours… just as guests, that’s how they received the neighbours, so the news spread quite fast. In this initial period it really helped a lot to overcome the prejudices. Then when the residents went somewhere, on a hike or to the theatre, others would ask where they had been, what they had seen. So they talked. Then, in this initial period, or rather after the first six months, the villagers started to get to know the residents and not to be afraid of them.”* (Mrs. Márton Dávid, head of institution)

Nowadays, it is typical of the everyday life of the residents and the villagers that they take part in the village events, jointly play soccer with the municipal team and attend sports trainings in the culture centre. Since this is a small village, there aren’t many opportunities for entertainment, that is why, when possible, they travel to Szentes to the baths, or go to see a theatre performance, and every summer for one week they go on holiday.

With respect to deinstitutionalisation, it is interesting to see what members of the personnel and social workers who have got used to large institutions think about the opportunities offered by group homes. It is a general experience that members of the personnel that work in group homes are able develop a relationship of different depth with the residents they take care of. What they describe is a much closer relationship, a possibility for which is provided by a group home.

> *"The residents can freely come and go. They sometimes follow me, we can do cooking or washing together. In various situations there are opportunities for chats or some sort of direction. We provide feedback to the residents on what they did well, or not, or when we are engaged in a routine task, then we can talk even about something else. In the institution this is not really feasible (…) In this kind of relationship you can get to know the residents better, they may open up more easily as there are such opportunities also in the evening when we eat our supper. When we have a nice conversation, we would spend as much as an hour at the table. Because then one resident would say something, then the other one, our colleague would also add something, asks questions, or … You can talk to them for a very long time at the table, for example, when we have a common meal. And that is very different. In the institution, there is a hall where they sit at the tables, and it is the nurse's duty to give out the supper, assign the medicine, so that type of work is different."* (Mrs. Márton Dávid, head of institution)

Síkvölgy (MERI)

Most frequently, we have the following image of a social institution: old building, crumbling plaster, here and there broken chequered tiles. Síkvölgy very much goes against this stereotype, since the institution that was established in the building of the 110 years old castle, as a result of the successful tender by the management and the personnel, both aesthetically and in terms of accessibility, can provide a harmonious living environment for its residents. In the tender announced by the Kingdom of Norway, the institution received a grant in the amount of 173 million HUF to be used in an investment of a total worth of 318 million HUF. During our visit we saw that the rooms are split into two parts, thus, although four people live in one room, owing to the division, two people live in one space. If they wish, there is a possibility for the residents to withdraw to their place which they themselves furnish and groom. The two-person division allows for couples to share one room. The management of the institution gives preference to this, as this type of attachment greatly facilitates the maintenance of the residents' balanced state of mind.

The residents have a possibility to do physical exercise in the gym, and there is also a small chapel for those who wish to practice their religion. In the institution, there are several activity-rooms equipped for various activities where the residents can freely choose how they wish to spend their time. These rooms offer an abundant choice of basic materials and tools for creative activities. When they become tired of one activity, then may switch to another, if they wish.

According to the personnel of the institution, part of the residents of the large institution do not intend to move out to either the group home situated in the garden, or to the house located in Vértesszőlős. They believe that the explanation for this is the circumstance that they became used to the care they receive in the institution which guarantees comfort (washing, meals). But this, at the same time, curtails their independence. They feel themselves powerless and cannot imagine themselves in this situation.

The director, Mr. Attila Szabó believes that, at the same time, this inner inhibition can in many cases be resolved by reinforcing the residents' self-confidence. There are several positive examples when residents of a large institution, overstepping their initial fears, started to efficiently organise their life from the very first day after moving to the group home in the garden.

Group homes in the backyard of the Institution

The fist tenders for group homes were announced 9 years ago, and the management immediately applied, as a result of which the first group home was built. According to Mr. Attila Szabó, head of the institution, at that time the profession held a dual judgment about this form of housing. Many believed that it is completely unnecessary, as the patients with mental health problems will only wreck the freshly built houses, and looked upon it as just one of the established set of EU requirements. Nevertheless, several positive results were known, such as cost-effectiveness compared to large institutions: based on local experience, its maintenance was 20 percent less expensive than in case of a large institution. Based on the director's experience, we can say that in Hungary there is no standard form of operation of group homes, since there are several places in which 10 residents are served by 8 caregivers. In contrast, the management of the institution in Síkvölgy holds the view that the main point of a group home is the higher degree of independence and autonomy which the residents can make use of, therefore, such a high number of caregivers is unnecessary.

There is no standardization in the issue of relocation, that is, there are no established criteria in who may try out the form of living that ensures a higher level of independence. The caregivers and the management jointly agree on who they consider suitable, later the management makes a decision on the relocation.

In the early days, when the group homes were built, the patients were not considered fit for moving out, and several residents were reluctant to break away from the opportunities offered by the large institution which they became accustomed to over time. However, experience showed that the majority successfully adopted to the new situation, and started to live their everyday life in a much more independent and balanced way (e.g. with less medicine). This duality became visible also among the personnel. There were members of personnel who welcomed this opportunity and looked at the unknown working method as a challenge, but there were also such who did not see the potential in the patients for creating a more independent way of living. The director said that, occasionally, less young residents are also moved out to the group home for rehabilitation purposes. For 10 years they can live a more independent life, but later, due to their age and condition when they are not able to take care of themselves, they are placed back in the institution.

Currently, there are three group homes in the garden of the Síkvölgy (MERI) institution. Due to the homogeneous design, one home accommodates people with intellectual disabilities, while the other accommodates people with mental health problems. Those residents who live in the large institution may not enter the group home without the permission of those living in it; residents of group homes have their own key to the building. One group home is composed of 5 rooms and 2 times 2 residents live in one room, hence, altogether 10 people make up a community. Here as well, the residents themselves are the ones who make their rooms cosier. Every one of them proudly showed their room and their objects that surround them. These rooms are real living environments, in no detail do they remind of the institution of which they are part. The entire house has the atmosphere of a large family holiday home, and not only with respect to the arrangement and equipment.

The group homes have their own kitchen and bathroom; a huge living room and a terrace offer common spaces. The task of tidying up is split up among the residents, although, the caregiver told us that in the initial period this can cause the most trouble as in the large institution this task is carried out by the cleaning personnel. In one group home inhabited by people with mental health problems we had an opportunity to make an interview with the residents about their everyday life.

They told us that they often cook along with having their meals in the large institution, and that they do the washing themselves. There is a snack-bar from where they can order and buy the ingredients for the cooking. There are several couples in the home that live in one room; one such couple has lived in a relationship for 9 years, the other one for 14 years.

At the beginning, the residents were unwilling to move out, they had an aversion for the situation. But after a while they realised that it is going to be a much better living environment. Each of them strongly emphasized the quiet as the main reason which is ensured in the group home compared to the large institution. According to their caregiver, it took approximately one year to establish with the residents the trust needed to talk, instead of only sitting in their rooms in a passive way, alone. Since then, all of them have found their place and rhythm. According to the caregiver, the best therapy is a conversation itself, given the fact that there is time and space for this, and the relationship that has developed in this way greatly facilitates collaboration and realisation of the community life. Fluctuation is not typical within one community.

Residents of the group homes maintain a relationship with their family much more intensively and more often. There is a possibility for the family members to spend the night with the resident in the group home. The caregiver also told us about a woman who was over an alcohol addiction rehabilitation treatment and who at that time was allowed to meet her children who were under state care only for 30-minute periods. At the time of the visit, she maintained a stable relationship with her children who lived in foster care. This woman may spend more time with her sons at the foster parents’ place, and also she is allowed to spend the night there. Recently, she took part in her son’s graduation ceremony.

Typically, the residents who live here carry out work within the institution: they do gardening, wash dishes, sweep, and they get paid for this. Unfortunately, possibilities for work outside the institution are limited, said Mr. Attila Szabó. Generally, the employment programmes which are launched by organisations with an investment of a lot of money, time and energy, following a powerful initial start, due to the specificity of financing, are interrupted despite the circumstance that these are very high standard job opportunities organised in the open labour market, that is, all this is about real integration. Another significant loss in this situation is caused when the motivation and confidence raised in many people are annulled with one decision when the project-based programmes end.

From a financial aspect, after years of operation it became clear that maintenance of group homes is more cost-effective than maintenance of large institutions. Also, importantly, all group home residents who we spoke to told us that they much preferred to live here than in the large institutions, that they liked the quiet, the assurance of the community as well as taking care of themselves, which clearly appeared in their self-image in a powerful and positive way, all of which they do not perceive as a burden.

External group home in Vértesszőlős

We arrived at the group home when its residents were away. The group home is established in a renovated old cottage, located in an integrated way, and, similarly to the large institution, is well equipped and caters for all needs. The building with orange painted walls and will plastic doors and windows also has a large garden. The building and its environment are liveable in all aspects. Although we spent only a few hours there, we did not have any strange feeling about it. When one of its residents arrived home, we received an insight into the everyday life of the home.
Their daily routine is not different at all from that of the people who live an independent life: in the morning an alarm clock wakes them up, then they go to work. Some of them work in Esztergom, others travel back to Síkvölgy to take part in social activities, but work has become part of their daily routine. After work they take care of the duties in the group home. They share the chores that need to be done in the home and around it, with respect for, and control of, each other. They live independently of each other, still, with a degree of dependence on each other, in the positive sense of the word, the men do the work that requires physical fitness, while the women do the cooking, and on each occasion they invite the others to share the cooked food with them. There is strong community cohesion, and in the course of the years it has proved to be stable. Two people live in one room which they have shaped and decorated to meet their own needs, with responsibility and duties as to their living environment.

After leaving the large institution, it still ensures for the residents of the group home a supportive background. When they need support or assistance, they know who to turn to. Still, they would not go back to the large institution. It was in the first place the quiet, peacefulness and the opportunity for privacy that our conversation partner mentioned as the primary advantages. It is apparent that they like living here, in this way, independently, abiding by their own rules. What remains with respect to the helplessness and passivity that they acquired in the institution is only bad memories. Standing out themselves, they are motivated about their own fates and everyday lives.

Living in rented property

The highest degree of integration is independent living in the community. In the case of the Síkvölgy institution, it means rented property which institutionally does not belong to the institution, it is the rented property of the residents themselves. Each year, several residents move out of the institution to start living in rented flats, and, as we mentioned before, it is not necessary to go through all the institutional steps for this. It is the opinion of the management that matters when it comes to moving out of the institution. It is clear that this type of housing means the highest level of independence. In it, the (former) patients, entirely dependent upon themselves, live their everyday live.

In Hungary, moving into a separate rented flat is one of the highest forms of social integration for people with disabilities. This is already a way of living that is exercised by hundreds of thousands of people in the country. A person with a disability who lives in rented property turns from patient into an independent citizen. People who live in rented property themselves pay the costs, and when they need help, the conditions are no different from those when anyone of us turn for help. This is even more so since the institution does not receive additional funds for the after-care. Individuals who rent a property can pay a visit to their caregiver in the institution, can discuss issues, and thus resolve the after-care.

In our view, the implementation of the multi-stage group home accommodation in Síkvölgy serves a number of functions. It has downsides as well, since the punishment-reward function of the group homes is currently still an existing dimension. One can see that those residents who live in the group home consider it a privilege to live there compared to the rest of the residents in the large institution.

We believe that group homes established in the courtyard of institutions are one of the bogus solutions of the characteristic Hungarian care provision system which reinforce, rather than eliminate, the large mass institutions. It is unquestionable, however, that in Síkvölgy by creating further stages of moving out, the group homes located in the courtyard came to life. They have become a kind of test-field for the unfolding and maintaining of independence, as well as development. For many people for whom this improvement that was implemented in a protected environment ended with encouraging results, the next step forward is the group homes that is located 20 km away from the institution, in an integrated environment indeed, from where they can successfully move on to the third stage, already a truly independent living environment.

We believe that, with this gradual deinstitutionalisation strategy, the Síkvölgy institution belongs to those few rehabilitation institutions which, in compliance with its name, offers real rehabilitation opportunity, and which has accumulated considerable experience in the area of promotion of independent living. We hope that it will belong among those institutions which will be included among the first participants of the deinstitutionalisation programmes financed from the upcoming European Union funds.

Summary

In the above, using relevant sources, we have attempted to outline the policy developments related to deinstitutionalisation of large institutions, and to shape our opinion in connection with those. In the course of processing the events, we covered the period from the change of government in 2010 up until the end of the year 2011.

In this year’s report, it is the results of two surveys that we presented. In the summer of 2011, we carried out interviews with representatives of institutions that are potentially affected by deinstitutionalisation and their maintainers, and through two specific case studies we presented two endeavours in which institutions gained experience through implementing deinstitutionalisation.

On the whole, we believe it is an encouraging fact that the paralytic state that was characteristic of the period between 1998 and 2010 developed into an active period of real action which points towards deinstitutionalisation. Nevertheless, in this process, certain key principles recommended by international organisations and relevant policy documents seem to be violated, which can seriously endanger the success of deinstitutionalisation in Hungary.

One of the fundamental requirements of the success of a comprehensive restructuring process which directly affects the life of several tens of thousands of people with disabilities, and about the same number of professionals, is that it shall be based on a broad consensus and a clear policy determination. However, from the above detailed sources it rather seems that, although there is a perceived political will for the implementation of deinstitutionalisation, the civil and professional actors who have anyway long been calling for this process, and the institutional side which has shaped its doubts and uncertainty, are dissatisfied with its content and details.

The policy planning and the consultation which took place along it failed to happen with the necessary meticulousness. The deinstitutionalisation process which has just been launched is not the result of a matured process based on a consensus, but is a process that the decision maker consistently pushed through along the pre-set positions, from the first communication until the last provision.

It is particularly indicative that, although the national decision makers – in their professional documentation and external communication – make regular references to our obligations undertaken under the international agreements and the recommendations of international organisations, in reality, the national deinstitutionalisation strategy was adopted in such a way that, despite the significant criticism by the international experts and their recommendations, it has also provided the possibility for establishing further large institutions (this time for 50 people). Neither the professional arguments on the national level, nor the international recommendations were able to achieve a change in this.

The fact that the process of deinstitutionalisation can be launched in 2012 from European Union funding is in itself a progressive development, but what is warning is that we are trying to replace the legacy of the rigid, hierarchic system along a very similar rigid, hierarchic policy consultation mechanism. There is still serious tension and disagreement among the system's various stakeholders who, independently of each other, have been trying to enforce their ideas through publicity, or through advocacy channels elaborated in the course of decades. Symbolic spaces which may create professional consensus fail to come into existence, or if they do, with a content which does not leave possibility for intervention in the really substantial issues. Thus, a central will that has been seriously criticised from both sides prevails, rolling ahead the existing tensions of the system.

What we see as good news is that the two case studies have clearly shown that there are positive examples of deinstitutionalisation in the Hungarian practice. Although, not a single institution has been closed down in Hungary as a result of successful deinstitutionalisation, we have seen examples where, with spectacular professional results, in several places people who used to live in institutions have been integrated into the community. All this despite the earlier initial resistance of the local population, and/or the current personnel. At the same time, the current domestic solutions, in an unusual way, are still reinforcing, and simultaneously weakening, the system of large institutions which, on the legislative level, has for 14 years been sentenced to dissolution. The majority of our group homes operate as sideline branches of the institutions, closely connected to them. On the example of Síkvölgy, we could see that the establishment - with excellent results - of a rehabilitation system of moving residents out of an institution could take place at the same time as the renovation of the large institution worth of several hundred millions of forints.

This duality which is the result of unprocessed “for and against” arguments and of the inadequacies in the area of reaching a consensus, eventually leads to the emergence of a parallel, growing care provision system which, as we already pointed out in our earlier studies, places an untenable burden on Hungary. On our part, we maintain our position that there is a need for an explicit commitment for deinstitutionalisation which has to be implemented in a resolute way, taking seriously each element of it. Compared to this, we repeatedly come to the conclusion in our studies carried out in this issue that the differing interests push the decisions both in the direction of institutional development and that of deinstitutionalisation, by which the costs of the reforms are doubled, and the entire reform process is pushed away into the infinite uncertainty.

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