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Deinstitutionalisation in Hungary  
2012-2013

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"And here comes the deinstitutionalisation, the castration of the institution."  
(excerpt from an interview)

## 1. Background

Since 2010, on a yearly basis, the Faculty of Social Sciences of the University of Eötvös Loránd (ELTE) in cooperation with the Soteria Foundation has published<sup>1</sup> its research studies on the current developments of deinstitutionalisation in Hungary. This year we continued our research in the framework of an independent working group<sup>2</sup>. The research was supported by the Mental Health Initiative.

Based on three analyses, our current study examines the developments in the field of deinstitutionalisation in Hungary. Ms. Zsuzsa Kondor processed the activities pursued by the Coordinating Board for Deinstitutionalisation based on public records and interviews made with the members of the Board. Mr. Zsolt Bugarszki summarized the interviews carried out with the personnel of the four large institutions which had applied for deinstitutionalisation and the conclusions of the analysis made of the needs assessment. Ms. Orsolya Eszik described the developments of the mentor programme intended to help the process of deinstitutionalisation. Similarly to the earlier ones, we prepared this research study based on a specific role. Although the issue of deinstitutionalisation is a policy issue that is financed both by the European Union and the Hungarian public funds, therefore is an issue of public interest, in fact it is very difficult to obtain information about the details of the decision-making mechanism and those of individual projects.<sup>3</sup> For years, our research team has been able to follow up the process directly by obtaining information through an active participation in the work of those bodies which shape the events. This is how we acted earlier in the Tender Preparatory Working Groups, and now in the body which coordinates deinstitutionalisation.

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<sup>1</sup> Previous research studies on this topic were:

Zsolt Bugarszki, Orsolya Eszik, Miklós Szentkatolnay and István Sziklai „One step forward, two steps backwards” 1-2 - 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 Faculty of Social Sciences.

Zsolt Bugarszki, Orsolya Eszik, Miklós Szentkatolnay and István Sziklai (2011): Deinstitutionalisation and Promoting Community-Based Living in Hungary, Budapest, Soteria/Faculty of Social Sciences of the University of Eötvös Loránd

<sup>2</sup> The authors wish to express their gratitude to the Hungarian Civil Liberties Union (TASZ) for the technical help provided by the organisation.

<sup>3</sup> On this, see in our previous study: Zsolt Bugarszki, Orsolya Eszik, Miklós Szentkatolnay and István Sziklai „One step forward, two steps backwards” 1-2 - 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 Faculty of Social Sciences.

We also find it important to point out that the authors of this study do not view the process of deinstitutionalisation from an independent, neutral position. The authors are committed supporters of the idea of deinstitutionalisation in Hungary. Our research is not primarily for academic purposes. The selected methods and the objective of the study is to support the process of deinstitutionalisation, to explore the factors which may hamper its successful implementation and to make recommendations.

## 2. Definition of Deinstitutionalisation and of Community-Based Living

When we speak about deinstitutionalisation, it is essential also to provide a correct definition of the institution itself. The Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care,<sup>4</sup> published in the 2009, interprets institutional care as a system in which institutions provide housing conditions in a segregated environment. It refers to the size of the institution as one of the fundamental aspects of the definition, based on which it considers to be an institution those forms of living which offer capacity for 30 or more people.

However, the document emphasizes that this figure is only one indicator, one dimension of institutional care, and considers it to be a useful tool especially with respect to statistical data collection. However, the document clarifies that the larger the institution, the more likely it is that the criteria for personalized service are not met, which leads to the development of the institutional culture. In contrast to the former, the study gives preference to the human rights approach which takes into account the users' dignity, the quality of life, health, autonomy and social inclusion. Thus, it considers those forms of service to be institutional residential services in which the institutional culture has developed.

On the whole, the research study sets out three criteria based on which it considers a certain residential service to be an institution.

- It isolates users from the community/society and forces them to live in cohabitation
- Users do not have sufficient control over their own life and over the decisions that affect them
- Institutional requirements take precedence over users' individual needs.

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<sup>4</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care - European Commission Directorate- General for Employment, Social Affairs and Equal Opportunities, Brussels, 2009

This definition was subsequently taken over by the Guideline<sup>5</sup> released in 2012, and also by the Action Plan adopted by the Committee of Ministers of the Council of Europe (CoE) in 2006 in connection with the new forms of community-based living which came about as the result<sup>6</sup> of deinstitutionalisation.

The objective of the Action Plan is the enforcement of the rights of people with disabilities for the period of 2006-2015, the promotion of their participation in society and the improving the quality of their life. The Action Plan identifies 15 major action areas, including the area of community-based living.

Instead of institutional care, the Action Plan gives preference to community-based living, and lists here, for instance, independent living and small group homes. It explains that, although fully independent living is not appropriate for everyone, even in such exceptional circumstances it recommends the solution of small, high-quality group homes. Furthermore, the Action Plan sets out the need to involve people with disabilities and the advocacy organisations which represent their interests in the elaboration of independent living.

On the whole, the Action Plan sets out three general objectives:

- to empower people with disabilities to plan their own life and to live, if possible, an independent life within the community,
- to provide access to a variety of quality community-level services in order to offer people with disabilities a possibility of making real choices,
- particular attention must be paid to the situation of families with a child/children with disabilities; support must be provided to parents concerned to ensure the opportunities for them to participate in appropriate training programmes, as well as to parents with disabilities to assume their role in their children's upbringing.

The Action Plan specifies flexibility and inter-ministerial cooperation as a basic condition for the achievement of these objectives and policies.

### 3. People with Disabilities and Residential Mental Health Institutions in Hungary

According to the data of the 2011 census, 456,638 people - 4.59 percent of the population, while according to the 2001 census, 577,006 people - 5.7 percent of the population were people with disabilities. In 2001, 7.9 percent of the people with disabilities (14,483 persons) lived in institutions,

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<sup>5</sup> Common European Guidelines on the transition from institutional to community based services (2012 ), European Expert Group on transition from Institutional to community based care, Brussels

<sup>6</sup> Committee of Ministers Recommendation Rec(2006)5 to member states

and 69.4 percent with their family. In view of the correlation of the people living in institutions and the types of disability, people with intellectual disabilities represent the highest proportion (47.5 percent). There is a much lower proportion of people with physical disabilities (20.1 percent), people with visual impairment (10.2 percent) and hearing impaired people (6.4 percent). Compared to the non-disabled population where the proportion of people under age among the people living in institutions is the highest, children and the elderly are over-represented among people with disabilities.

According to the 2011 census data, the number of people with mental health problems is 46,265. Among them, according to the data of the CSO, in 2011 there were 8,785 people living in long-term care and 104 people living in temporary care, thus a total of 8,889 people with mental health problems lived in residential institutions, which is 19.21 percent of the population with mental health problems. Also in 2011, there were 2,061 people with addictions living in long-term care and 125 people living in temporary care.<sup>7</sup>

From the point of view of deinstitutionalisation, the data on institutions providing nursing and care for people with disabilities whose capacity exceeds 50 beds are decisive since, according to the Deinstitutionalisation Strategy, they are the target group of the Hungarian process of deinstitutionalisation.

However, it is worth noticing that the call for applications for the "A" component of the social institutions, the Social Infrastructure Operational Programme (TIOP)-3.4.1.A-11/1 for deinstitutionalisation of residential institutions also covers the groups of people with mental health problems and people with addictions, thus, in a peculiar way, the call for applications announced by the NDA (National Development Agency) overrode the deinstitutionalisation strategy adopted with the government decision.

#### 4. Current Regulatory Environment for Deinstitutionalisation

With its Act XCIII of 2007, Hungary ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Thus Hungary recognized, among others, "the right of persons with disabilities to be included in the community and to have choices equal to others", as formulated in Article 19 of the CRPD. For the achievement of which it will take all necessary and effective measures. The countries which recognize the Convention shall ensure that people with disabilities have the opportunity, on an equal basis with others, to choose the place of their residence, and where and with whom they wish to live, to have access to a variety of home, institutional and other

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<sup>7</sup> Social Statistical Yearbook of the CSO, 2011

community-based services, and that community services and facilities should be accessible, on the same grounds, also for people with disabilities."

Act XXVI of 1998 on the Rights and Equal Opportunities for Persons with Disabilities envisages deinstitutionalisation of social institutions which provide nursing and care for people with disabilities with a capacity exceeding 50 beds, and states that deinstitutionalisation shall be implemented taking into consideration the requirements of Article 19 of the ratified UN Convention referred to above. It specifically states that "institutional capacity for at least 1,500 people with disabilities and people with mental health problems must be deinstitutionalised with EU co-financing by 31 December 2013." This provision was included in the Act XXVI of 1998 by Act XCIII of 2007.

According to the previous version of the law, "long-term residential institutions must be transformed, by 1 January 2010 the latest, in such a way that people with disabilities who are able, with support, to live independently must be placed in group homes, while care for people with severe disabilities must be ensured in a modernized and humane environment."

Thus, from the point of view of deinstitutionalisation, Act XXVI of 1998 has decidedly changed in a positive direction, since the new law does not interpret the care for people with high support needs separately, and with respect to them goes beyond modernization of the existing large institutions, thereby taking away the legitimacy of large institutions.

At the same time, however, it is important to notice the practice by which the legislative body, by amending the statutory deadline, extends the deadline and thus legitimises the delay.

In line with the above phenomenon, the relevant provisions of the effective Act XXVI of 1998 are considerably softened by the circumstance that, in accordance with the deinstitutionalisation strategy, transforming institutional capacity that will not have been deinstitutionalised by 31 December 2013 may be carried out in a way determined by the Government. This also makes the fate of deinstitutionalisation in the period after 31 December 2013 very uncertain, and will make deinstitutionalisation highly dependent on the commitment of the respective government.

The 50-bed institutional capacity threshold set in Act XXVI of 1998 contradicts the 30-bed threshold specified in the international recommendations, which in itself is only one particular dimension of the definition of deinstitutionalisation, but crossing it increases the likelihood of developing the institutional culture. Act XXVI of 1998 Its review is still in progress.

From the point of view of deinstitutionalisation, Art. 57(3) of Act III of 1993 also has a great importance, as it sets out that

"After 1 January 2011, new capacity for the provision of institutional care and nursing for people with disabilities can be established only in the form of group homes."

With this it intends to prevent a further expansion of the existing total system of institutions, which would be against the spirit of deinstitutionalisation. This paragraph was amended by Article 24 of Act

LXXVI of 2012, while the third paragraph which we have emphasized was repealed by Article 12(6) of Act CXVIII of 2012 as of 1 January 2013.

It was replaced by a new provision, Article 11(2) of Act CXVIII of 2012. The text currently in force, in accordance with Art. 140/P, stipulates that:

"As of 1 January 2013, new institutional capacity intended to serve the purpose of providing institutional nursing care for people with disabilities, people with mental health problems and people with addictions, in case of transformation of large institutions can only be established as supported forms of independent living, in case of establishing new institutions may be set up only in flats or houses for up to six people, or in flats or houses for seven to twelve people."

In case of deinstitutionalising large institutions, the new regulations thus allow to establish - in the tender terminology - flats, group homes and residential centres, but in case of creating a new institution the law leaves the possibility only for establishing flats and group homes.

This dichotomy seems illogical. However, the change is positive in the sense that, while the former provision applied only to institutions for people with disabilities, the new legislation has expanded it to institutions providing nursing care for people with addiction and people with mental health problems, in line with the target as defined in the call for applications TIOP 3.4.1.

Supported community-based living as a form of care was included into the Social Act through Art. 7 of Act CXVIII of 2012 which has been in force since 1 January 2013, and it better reflects the more complex approach of deinstitutionalisation which goes beyond the concept of the housing dimension. According to Article 75 of the Social Act,

"the scope of supported living includes housing services, case management that promotes independent living, accompanying support which takes into account the living conditions of the person who receives care, the individual's complex needs assessment and an optional support services in the area of meals, nursing care, development and participation in the social life of the community."

The Article names three types of housing services: "a flat or house designed for up to 6 people, a flat or house designed for 7-12 people, and flats or an ensemble of buildings designed for a maximum of 50 people." Thus, similarly to Act XXVI of 1998, the limit of 50 people as the maximum authorised capacity appears here as well.

Act III of 1993 names people with disabilities, people with mental health problems and people with addictions, as well as homeless people as the target groups of the care service. This broad definition of the target group is forward-looking because it carries the possibility for the process of deinstitutionalisation, in case of a positive outcome, to include all groups in the future. The Guideline published in Brussels in 2012 describes deinstitutionalisation as a process which affects children, people with disabilities, people with mental health problems and the elderly. Thus, in the comparison

with the Social Act, the Guideline lists children and the elderly as a new target group, but fails to mention the group of homeless people named by the Social Act.

Article 85/A of the Social Act separately specifies the group home services.

"A group home is an institution which provides care for 8-12, in cases specified in separate legislation for 14 mental health patients or people with disabilities, including autistic persons and people with addictions."

Group homes, similarly to supported living, shall ensure "the services taking into consideration age, state of health and self-sufficiency of the users." However, this type of care is rather housing service-oriented and does not contain such a complex package of services as supported forms of living, and also fails to name homeless people as a target group.

Article 92 of Regulation 1/2000 of the Ministry of Social and Family Affairs states with respect to group homes that

"irrespective of the characteristics of the institution, separation of the residential and work related tasks and leisure time must be ensured, and, to the extent possible, shall ensure employment or recreational activities, as well as their organisation."

This sentence is somewhat controversial and can give a basis for misinterpretation, because first it sets out a commitment that residential and work related tasks and leisure time must be separated, then suggests, as a possibility, that a group home may provide employment and possibly recreational activities as well. The reason why I believe this detail is important is that, also with respect to the forms of living which come about as the result of deinstitutionalisation, the call for applications TIOP 3.4.1 also includes the separation of the scene of housing, work and leisure time as an important criterion. However, it is worth noting here that Article 140/P of the Social Act envisages to take the group home as a form of care out of the system of providing residential care before 31 December 2014.

A law closely associated with deinstitutionalisation is Act IV of 1959 on the Civil Code of the Republic of Hungary. This law was amended in 2013, but it still includes the possibility that people with disabilities, people with mental health problems or people with addictions may be placed under guardianship that limits, or rules out, their ability to act. This regulation goes against the UN Convention on the Rights of Persons with Disabilities ratified by Hungary in 2007, as the preamble to the Convention requires

"the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms, and the need to ensure for persons with disabilities their full enjoyment without discrimination." (Act XCII of 2007)

According to CSO data, 53,830 people were under guardianship in 2011. This number has steadily increased since 2000 (40,838 people).<sup>8</sup>

The Hungarian regulation illustrates the situation which was well formulated by Thomas Verdes that, although in Hungary people with disabilities have certain social rights, they are not based on the civil and political rights, while these should function by strengthening each other.<sup>9</sup> This also questions the outcome of deinstitutionalisation, since the Hungarian regulation fails to view people with disabilities as full citizens, which is contrary to the provisions of, and the image of people with disabilities specified in, the CRPD.

## 5. Changes in the Maintenance Affecting Large Residential Institutions

Deinstitutionalisation of institutional capacity in itself entails a huge change both for the affected individuals and the professionals who take care of them, as well as the organisations which maintain the institutions. Virtually simultaneously with the launch of the implementation of the Deinstitutionalisation Strategy, another similar far-reaching change took place as well.

Based on Act CLIV of 2011, as of 1 January 2012, the social and child protection institutions earlier maintained by county governments came under the maintenance of the state, hence the specialised care of people with disabilities as well. Act CXCII of 2012 on the transfer of certain specialized social and child protection service institutions to state ownership and on amending certain laws regulates the transfer, as of 1 January 2013, of institutions that were earlier maintained by local governments to the state. The new owner is the Social and Child Protection Directorate-General. The change affected institutions specialized in the area of child protection, disability, addiction and mental health. Thus, most of the long-term residential institutions in Hungary came under the supervision of a single central maintaining body.

This change has a serious impact on the process of deinstitutionalisation as well. In fact, as a result, a new actor, the Social and Child Protection Directorate-General stepped in the shaping of the process of deinstitutionalisation, and those actors which used to have a powerful lobbying force, namely local governments which until recently had been maintainers of the institutions, have been marginalized. In this study, for the time being, we did not undertake to assess how this change may affect deinstitutionalisation in Hungary. Firstly, because it is very new and these are still ongoing events; on the other hand, because this topic in itself is worth a separate analysis.

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<sup>8</sup> CSO, Information Database, data on guardianship authorities (2000)

<sup>9</sup> Thomas Verdes (2009): "The House Is Owned by the Institute," In: Chances 2009/4 pp. 92-112

## 6. Call for Tenders TIOP 3.4.1."A"-11/1

The Social Services component of the call for applications TIOP 3.4.1."A"-11/1 was announced on 27 January 2012, after the Strategy which had been set as a condition for the call had been completed. Although the call for applications was elaborated in line with the Strategy, with respect to certain points there are differences. In fact, the call for applications, already in its own right, makes people with mental health problems and people with addictions targets of deinstitutionalisation, expanding thereby the group of people with disabilities. This definition is already broader than that in Act XXVI of 1998, as it includes people with addictions as well.

Despite the national and international debates, the call for applications, too, provides the opportunity for establishing forms of housing for up to 50 people. It specifies three types of forms of housing: the flat, the group home and, "in special cases", the residential centre for up to 50 people. However, it defines the latter as "an ensemble of buildings with a flat-type structure."<sup>10</sup>

The call for applications specifies that the users' "work environment must be arranged separately from their housing and the provision of service during the day."<sup>11</sup>

The definition of deinstitutionalisation in the call for applications includes "deinstitutionalisation of institutional capacity with respect to the total capacity and the provision of integrated housing services"; in addition, the call for applications also includes "a wide range of services supporting, and empowering for, self-care", "training for those moving in the new forms of living and for those providing the services for users, as well as sensitizing the new living environment".<sup>12</sup>

The budget of the tender is HUF 7 billion which the tender wishes to utilise specifically in the convergence region. The tender will be co-financed by the European Regional Development Fund and Hungary's budget, and since it is a TIOP programme, Hungary's contribution will be 15 per cent.<sup>13</sup>

A total of six applications were received in the call for applications, according to the submitted feasibility studies for deinstitutionalisation of 701 beds. Unfortunately, this is less than half of the capacity planned in the Strategy for the first three years.

As a result, according to the submitted applications, 6 residential centres, 40 group homes and 19 flats will be built.

Total amount of support won by the candidates: HUF 5,867,328,071 / EUR 19,344,327.82.

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<sup>10</sup> Call for applications TIOP 3.4.1."A"-11/1

<sup>11</sup> Call for applications TIOP 3.4.1."A"-11/1

<sup>12</sup> Call for applications TIOP 3.4.1."A"-11/1

<sup>13</sup> Call for applications TIOP 3.4.1."A"-11/1

Within the framework of our current research program we didn't analyze the details of TIOP 3.4.2 program which is designed to support the renovation and modernization of residential homes. We have done it earlier, in 2011<sup>14</sup>, when we found that according to the decision makers only residential services having less than 50 beds could receive funds from this program. The first round of the tender has been implemented like this in 2008.

HCLU (Hungarian Civil Liberties Union) has explored that in the following rounds of the tender spite of the formal decision institutions with more than 50 beds also received money from these sources:

- The renovation and extension of a facility for people with mental health problems (82 + 20 residents in two building) in Símaság, funding amounting to €550.000.
- Reconstruction of the Endre Piróth Social Care Home for Psychiatric Patients (350 residents) in Táplánypuszta, funding amounting to €436.487.<sup>15</sup>

## 7. National Coordinating Board for Deinstitutionalisation of Institutional Capacity

Government Resolution No. 1257/2011 (of July 21) (the Strategy) put an obligation on the Minister of Human Resources to establish the National Coordinating Board for Deinstitutionalisation of Institutional Capacity (IFKKOT), which, as a result, was set up on 11 August 2011. The objective of the Board was defined as coordination of the Strategy's implementation in which guidance shall be drawn from the principles and objectives of the Strategy.

With respect to the composition of the Board, at its first meeting two people represented the then Ministry of National Resources, the Social Services and Child Welfare Department and the Department for Disability Issues. Two participants represented the social background institutions, the National Family and Social Policy Institute and the Public Foundation for Equal Opportunities for People with Disabilities. Two participants were from advocacy organisations representing people with disabilities, the Hand in Hand Foundation and the National Disability Council. One participant represented higher education institutions of special education via the Special Education Faculty of ELTE, one person represented maintainers of state-owned social institutions via the Social Policy Department of the General Department of Health and Social Affairs at the Budapest City Hall. And one individual represented the maintainers of non-state-owned social institutions via the National Association of Non-Governmental Organisation and Foundations for People with Intellectual Disabilities. Ms. Csilla Szauer (Public Foundation for Equal Opportunities for People with Disabilities) was elected as the president of the body.<sup>16</sup>

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<sup>14</sup> Zsolt Bugarszki, Orsolya Eszik, Miklós Szentkatolnay and István Sziklai (2011): Deinstitutionalisation and Promoting Community-Based Living in Hungary, Budapest, Soteria/Faculty of Social Sciences of the University of Eötvös Loránd

<sup>15</sup> Unpublished data explored by HCLU

<sup>16</sup> Minutes of IFKKOT meeting 1/2011 (of August 11)

Following the first meeting of the Board, several organisations, among others the Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ) also expressed their protest and declared their intention to participate in the work of the Board.

As a result of the protests, the Ministry decided to expand the coordination body. On behalf of advocacy organisations representing people with disabilities, the Council of Organizations of People with Disabilities (FESZT) was asked to represent itself via its current president, thus already three people from advocacy organisations representing people with disabilities were present in the Board. Also the size of the Board increased by an additional representative, that of the maintainers of church-run social institutions.<sup>17</sup>

According to the minutes of meeting 6/2011 (of November 17), Ms. Csilla Szauer, Chairman of the Board, suggested the expansion of the Board by three additional members. Accordingly, in the future, a representative of the body for the protection of the mental health patients' interests will participate in the work of the Board, as well as one person from the area of social higher education, and, after the establishment of the Civil Workshop, one civil representative. The Board approved the proposal unanimously. Deputy Secretary of State Ms. Erika Asztalosné Zupcsán agreed with the enlargement and the invitation letters were sent to the nominating organisations.<sup>18</sup>

Thus, in summary, the participants in the Boards are: the Ministry of Human Resources (2 members), Social Background Institutions (2 members), people with disabilities and advocacy organisations of people with mental health problems (4 members), institutions of higher education in the area of social sciences and special education (2 members), state, civil and church maintainers (3 members), and the Civil Workshop (1 member).

As of 1 January 2013, this composition changed only in that Ms. Lívía Korinek, deputy director of the National Family and Social Policy Institute, is no longer included among the members, thus the number of representatives of social background institutions was reduced to one. The Public Foundation for Equal Opportunities for People with Disabilities (FSZK) is represented by Ms. Edit Farkas who since 19 February 2013 has been the chairman of the organisation.<sup>19</sup>

Also, as of 1 January 2013, Ms. Judit Pintér on behalf of the Social and Child Protection Directorate-General became a member of the body. With this, the number of members on behalf of maintainers increased to four. As a result, the two groups with the largest number of representatives in the board: the maintainers and the advocacy organisations of people with disabilities and of people with mental health problems.

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<sup>17</sup> Minutes of IFKKOT meeting 2/2011 (of September 8)

<sup>18</sup> Minutes of IFKKOT meeting 8/2011 (of December 7)

<sup>19</sup> Minutes of IFKKOT meeting 14/2013 (of February 19)

A specific task the Board has is to provide a preliminary opinion on the Feasibility Studies (FS) submitted by the candidates, whereby it carries out a preliminary professional assessment, drafts professional proposals in relation to the applications, monitors the developments, provides opinion on the concept of utilisation of the infrastructure remaining as a result of the institutional transformation and on the professional training, supervises their implementation, reviews the basic service capacity, ensures full transparency and develops an Institutional Transformation Action Plan. The elaboration of the Action Plan must be implemented once in 3 years based on the experience of the TIOP 3.4.1 call for applications.

As a condition for submission of applications, the call for applications TIOP 3.4.1. "A"-11/1 required the statement of support issued by IFKKOT, which increased the significance of the Board's previous professional work on evaluation. Therefore, the Board has the right of veto.

This right of veto was exercised by the Board, among others in the Kalocsa case in the first round of submitting Feasibility Studies. According to the minutes of meeting 9/2012 (of September 5), Szentes, Szakoly, Berzence and Bélapátfalva received statements of support, while the feasibility study submitted by Kalocsa was rejected. Subsequently, the Board also dismissed the request for review submitted by Kalocsa with reference to the procedural and technical aspects.<sup>20</sup>

Later no new call for applications was announced, but, for a short time, the possibility for submitting applications was re-opened. According to the minutes of meeting 11/2012 (of October 19), candidates had the possibility to submit feasibility studies by November 15, while a statement of support had to be issued by 15 December 2012. Because of the tight deadline, only the Institution Maintenance Center of the Szabolcs-Szatmár-Bereg County and Kalocsa had a chance in the second round.

The justification for this solution provided by the Ministry of Human Resources, namely, that there was no new call for applications, was that it could be announced only in 2013, thus the implementation period of minimum 18 months would be violated, and the Ministry feared that this would require a reallocation of resources.

It is important to note that, although IFKKOT's role cannot be questioned with respect to the implementation of the first wave of deinstitutionalisation, unfortunately, we cannot say the same with respect to the planning of EU's 2014-20 budgetary period. There are no signs demonstrating that the Board has discussed the future use of the EU Structural Funds which constitute the primary source of the deinstitutionalisation process in Hungary, or that it possibly consulted public administration bodies in connection with it. As of the date when this study was closed down

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<sup>20</sup> Minutes of IFKKOT meeting 10/2012 (of September 26)

(October 2013), no national body responsible for the implementation of deinstitutionalisation had raised its voice with respect to the use of future resources.

## 8. Interviews with Members of the National Coordinating Board for Deinstitutionalisation of Institutional Capacity

While, as we will see, the perception of the Coordinating Board is very diverse, at this stage of the deinstitutionalisation process we consider this body to be a determining factor. Beyond the formal decisions and arguments drawn from the minutes, through interviews made with its members we attempted to look into the relations within the IFKKOT and at the views its members had on deinstitutionalisation.

In the interviews we asked the participants about specific events and about the issues raised at the IFKKOT meetings, as well as tried to map the weight of individual policy actors in relation to deinstitutionalisation and the perception of the balance of power among them.

Interviews were carried out by Ms. Zsuzsanna Kondor who also attended a number of IFKKOT sessions as a representative of the Faculty of Social Sciences of the University of Eötvös Loránd.

Interviews were made with the following Board members:

- A professional staff member of the Ministry of Human Resources (MHR);
- Ms. Csilla Szauer on behalf of the Public Foundation for Equal Opportunities for People with Disabilities, President of IFKKOT until 31 December 2012;
- Ms. Melinda Kovács, Executive Director of the Hungarian Association for Persons with Intellectual Disability (FESZT);
- Mr. Ákos Pordán, Executive Director of Hand in Hand Foundation;
- Ms. Réka Vályi, Executive Director of the National Autism Association (AOSZ) who took part in the work of the IFKKOT as an invited expert;
- Mr. János Wisinger on behalf of the National Disability Council (OFT);
- Mr. Zsolt Bugarszki, assistant professor at the ELTE Faculty of Social Sciences;
- Dr. László Rubovszky, Executive Director of the National Association of Non-Governmental Organisation and Foundations for People with Intellectual Disabilities, as civil maintainer.

### Relationship to deinstitutionalisation and perception of the work of the body

The concept of deinstitutionalisation was interpreted by the respondents in a variety of ways, some in a narrower, others in a broader way. Most of them agreed that this issue is not only an issue of

infrastructure and does not simply cover the deinstitutionalisation of large institutions with programmes on family-type community-based living, but also targets the system to services which support independent living.

Some respondents had fears in their attitude towards deinstitutionalisation and had mixed emotions about it, but all of them were committed to the goal. Mr. László Rubovszky expressed his doubts but, at the same time, his commitment as well.

"How can we take seriously a person's desire about where they wish to live if, in the past decades, that person lived in conditions where the idea of the need for independent living did not even occur?"

"I had the opportunity in the past year to visit a few large institutions. And I believe that people there live in terrible conditions, which is a disgrace of the entire nation!"

The views voiced about the role of, and the power relations within, the IFKKOT were quite different among the respondent, although, on the whole, everyone recognized the importance of the role of the Board and defined it as a functional professional community. Nearly all interviewees noted that the members of the body which, in the beginning, was launched with large conflicts and a distrustful atmosphere among the different actors, in the past two years have arrived at a state of agreement. Although even today there are still serious disagreements in a number of issues, the discourse developed a culture that allows for a meaningful dialogue and the approximation of positions. In this respect, however, what is regrettable is that institutions which are directly affected by deinstitutionalisation have been left out of this important dialogue, since they are not IFKKOT members, and, as a result of the delegation solutions applied by the Ministry of Human Resources, real decision makers (heads of departments, Deputy Secretaries of State, Secretaries of State) are not part of the process either, thereby excluding themselves from the possibility of shared understanding and dialogue. Thus, currently there is no regular direct coordination and interaction of mutual influencing between the decision-makers and the IFKKOT members. Apart from the decision-makers, there is a lack of civil society advocates and the broader group of users, and, as we have mentioned, the institutional side is missing as well. The involvement of these actors into the IFKKOT would strengthen its role and legitimacy.

The composition of the IFKKOT was perceived by Mr. László Rubovszky and Mr. János Wisinger as unbalanced, because, in their view, the reform oriented advocacy groups are over-represented in it. In contrast, the advocacy organisations of people with disabilities, for instance on behalf of the Council of Organizations of People with Disabilities Ms. Melinda Kovács believes it would be desirable if all disability groups could be present in a representative way, and she does not see this as a difficulty of organizational nature. Ms. Melinda Kovács also voiced her criticism that these

organisations had not been not able to get involved in the planning process, which goes against the principle of "nothing about us without us", which is specified also in the call for applications.

Another issue that gives reason for concern is the proportion of theoretical professionals and practitioners in the Board.

"There is nobody in the IFKKOT who currently happens to be the director of an institution. From this point of view, the representation is distorted. Organizations which are engaged in the provision of everyday services that are affected by deinstitutionalisation are missing" (Bugarszki , Faculty of Social Sciences, ELTE)

"The IFKKOT does play an important role, and those professionals who are involved in it are able to perform at a very high professional standard. Unfortunately, however, the human rights-based approach is over-represented, and all decisions are subordinated to this approach. They tend to ignore the importance of the time factor, of the economic conditions, political will and any other accompanying arguments, and certain decisions are made along these lines. There are certain substantive issues which appear in a significantly different way as compared to the government's programme. Therefore, significant discrepancies occur in relation to the way a variety of items build on each other." (Mr. Wisinger, National Disability Council)

In connection with the role of the Board, Mr. Ákos Pordán highlighted the right of veto concerning the feasibility studies, which he defined as the most significant achievement. At the same time, several respondents indicated the lack of time, financial and human resources as a limitation in the meaningful work of the Board.

"We have much more work to do than the volume we can handle." (Ms. Melinda Kovács, Council of Organizations of People with Disabilities)

Ms. Melinda Kovács, on the other hand, also highlighted as the achievement of the Board that advocacy consultants and preparation of the residents had been included in the programme, and that the Public Foundation for Equal Opportunities for People with Disabilities and the Hand in Hand Foundation agreed with those candidates who are affected by deinstitutionalisation that residential centres would be created for a maximum of 25 people.

Ms. Csilla Szauer mentioned that the IFKKOT delegated members in all of the three working groups working on the ongoing review of Act XXVI of 1998, and indicated in advance that should Act XXVI of 1998 take over the spirit of the CRPD, it will affect both Government decision No. 1257 / 2011 (of July 21) and the Strategy. In connection with the amendment, Ms. Csilla Szauer pointed out the decision related to people with psycho-social disabilities who so far have not been included in the current Strategy on their own right.

At the same time, with respect to the Board, the Ministry of Human Resources shows a completely different perception.

The MHR does not perceive the Board as a powerful body. The Ministry feels it can be wiped away at any time. The Ministry faced the veto right of the Board in relation to Kalocsa. The leadership of the MHR did not really have an insight into the detailed process within the Board.

The Kalocsa application was rejected by the IFKKOT several times. The site visits and the professional analysis of the feasibility study did not convince the members of the Board that deinstitutionalisation in the city can be implemented in line with the requirements of the UN Convention.

A staff member of the Ministry of Human Resources said that Kalocsa is a municipal institution and that there are higher interests backing it which are above the level of the Ministry. In the first round, Kalocsa's FS was not accepted, however, in the second round it was. The staff member of the Ministry indicated as a danger in relation to Kalocsa that other interests moved the authorities of the city when the application was submitted than what the objective of the application was, especially since it was possible to apply for the largest amount of money. In relation to Kalocsa, with respect to the disagreement between the Ministry and the IFKKOT, the staff member revealed:

"I was surprised that the IFKOTT members were not replaced." (staff member of the Ministry of Human Resources)

There were several points of disagreement within the Board as well. One of the most controversial and most divisive issues was raised in relation to the residential centres for 50 people.

The Council of Organizations of People with Disabilities, the ELTE Faculty of Social Sciences and Ms. Csilla Szauer, former chairperson of the Board, do not consider the institution of residential centres acceptable.

Mr. László Rubovszky and Mr. Ákos Pordán consider the compromise appropriate in which an agreement was reached with the candidates in that, although both the law and the call for applications make it possible, they will not establish residential centres larger than those for 25-30 people, and no institution is included in the feasibility studies that is larger than that. Many consider it to be a significant achievement of the Board that, although the effort to convince the decision-makers in the domestic legislation which would be more in harmony with international recommendations failed, the Board's experts successfully influenced the candidates themselves.

"Although it was not our job, no one asked us, we still thought - in consultation with the Ministry - to discuss with the candidates that they should not plan residential units larger than those for 20-25 people. And, well, they accepted it. And the current FS is such that there are no residential units larger than those for 25 people, which I am not claiming is a guarantee for anything, but still it is evidence that some professional consensus may be under

way. And I think that this can serve as a foundation. It will be very difficult, very hard, but I trust in this." (Mr. Ákos Pordán, Hand in Hand)

A third type of viewpoint is that of the staff member of the Ministry of Human Resources who argued in favour of the residential centre. The staff member of the Ministry said that, from the point of view of the therapeutic community and the alternatives, they consider this form of living to be important. "Excluding one particular type of service may have the effect of constraint." And also "people have the need to live among people who are like them."

As an example he mentioned the elderly homes in Hungary. The staff member of the Ministry also noted that, in the call for applications, in contrast to residential centres, preference is given to flats and group homes, and that the selection of the form of housing must be made based on the Complex Needs Assessment.

In connection with the residential centres, a dissenting opinion independent of the number of inmates was also voiced in relation to the obligation for the separation of housing and other services, which is also laid down in the call for applications as a very important rule that must precede the development of the institutional culture.

"It is not always necessary to make flats, this can be done also with a central kitchen, with other professional central services. I think that such a studio can be solved on the hotel level as well. But this idea, again, should be left to the practicing professionals." (Mr. László Rubovszky, National Association of Non-Governmental Organisation and Foundations for People with Intellectual Disabilities)

## 9. Power Relations around Deinstitutionalisation

The power lines which, in our view, have always shaped the development of deinstitutionalisation in Hungary, precisely appear also in the work of the Board Coordinating Deinstitutionalisation. During the interviews, we attempted to present these power relations through the insights shared by the interviewed members of the Board.

We have the possibility to compare the image thus obtained with the analysis published by the Hungarian Civil Liberties Union (TASZ) and the Budapest Institute in 2012 in which they, too, attempted to map the power relations of the actors who have an influence on deinstitutionalisation.<sup>21</sup>

In their study, the authors considered the influential actors to be the most important ones. These include, among others, heads of institutions and personnel, leaders of local governments where

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<sup>21</sup> Tamás Verdes, Ágota Scharle and Balázs Váradi (2012): "Instead of the Institution", pp. 29,39-47, Budapest Institute, 2012.

there are large institutions, as well as politicians of county assemblies who are also seen as actors who fundamentally have a negative interest in the deinstitutionalisation process.<sup>22</sup>

The interviewees who we asked describe heads and personnel of the institutions which participate in deinstitutionalisation rather as people who stick to the old system. As resisting groups which have a strong lobbying capability, in line with the above classification.

"In a particular way, deinstitutionalisation in Hungary is left to the institutions, which may not be the best solution. It is problematic in itself to ask someone to liquidate their livelihood. At the same time, what is more problematic in the professional sense is that a service structure should be created for those who used to operate the old one, who have no other experience and expertise except for the operation of this old structure." (Mr. Bugarszki, ELTE Faculty of Social Sciences)

The professional staff member of the Ministry of Human Resources mentioned Szentgotthárd as a specific example. In Szentgotthárd there was an intention to implement deinstitutionalisation in a 15-kilometre radius to allow for the professional team to stay, which is contrary to the aim of the call for applications to make deinstitutionalisation happen in a geographically as wide an area as possible. The staff member of the Ministry mentioned Szentgotthárd as an example of old large institutions of which there are anecdotes like "if you set off from there, you will never get to Budapest alive." An interesting circumstance about Szentgotthárd is that it is a Budapest-based institution. In case the deinstitutionalisation of this institution is implemented in the way as planned above, the residents of the capital city would continue to stay hundreds of kilometres away from their original place of residence.

Service providers which operate the institutions are not members of the IFKKOT, hence they do not have much influence in the decision-making process. However, their real influence is still huge, as ultimately it is them who prepare the applications and they will implement them. Thus, their role and influence is undeniable, but they are strongly dependent on the IFKKOT due to the Board's right to veto feasibility studies.

Local government leaders who have a large institution in their municipalities have an incentive to keep the jobs secured by the large institution in place. The interviews also show that the local governments are interested in having the highest possible number of new real estates sold in their municipalities in relation to deinstitutionalisation. They are also moved by the housing lobby interests. This also makes it more difficult to enforce the principle according to which, in the course of deinstitutionalisation, residents' preferences must be taken into account when buying real estate.

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<sup>22</sup> Tamás Verdes, Ágota Scharle and Balázs Váradi (2012): "Instead of Institution", pp. 29,39-47, Budapest Institute, 2012.

The pressure exercised by local governments is mostly focused in the direction that the financial resources related to deinstitutionalisation be spent locally, while in several cases it was perceptible that they continue thinking along the logic of large residential institutions.

Until 31 December 2012, it was the politicians of the county council who had acted in the capacity of maintainers of a significant proportion of institutions affected by deinstitutionalisation. Today, however, these institutions are managed by the Social and Child Protection Directorate-General, a gigantic, centralized maintainer. Thus, since the time the analysis was carried out by the Budapest Institute, the role of the county council's politicians has moved to the background. Based on the interviews, a positive image emerges of the Social and Child Protection Directorate-General; the respondents look forward to the future and have hopes of partnership with the body in the process of deinstitutionalisation. This could bring a shift compared to the conclusions made by the Budapest Institute, and the Directorate-General may emerge as an actor with strong advocacy abilities and one that is motivated in the deinstitutionalisation process, which can give momentum to the process.

The Budapest Institute describes the Ministry of Human Resources, as it is known today, and the government as bodies of high-level capacity for advocacy, but usually as those with a low-level negative orientation.

Starting from the fact that the ministry prepared and the government adopted the Strategy on deinstitutionalisation, and that, unlike in other areas, it left EU funds allocated for deinstitutionalisation nearly totally unchanged, we came to the conclusion that on the decision-making level there is a positive commitment to the process of deinstitutionalisation. There is no doubt, however, that the way the government and the ministry, as part of it, envisage this process is different from that we can read about in the recommendations of international organisations. In our view, there is no doubt that the elimination of the traditional large institutions in Hungary has started. At the same time, the question remains whether the services that will be established will prevent the perpetuation of the institutional conditions in the new framework.

The median voters of the settlements that are affected by deinstitutionalisation are described by the Budapest Institute as individuals exerting neutral and powerful pressure. In contrast, the example of Bélapátfalva, and recently of Szilvásvár, show a different approach: there was a heated protest by the residents, and, as a result of their pressure, it seemed for a long time that Bélapátfalva would not establish new forms of supported living in the settlement, but these would be set up in the neighbouring settlements. The picture is further diversified by the circumstance that, in contrast to the two above-mentioned settlements, in Mónosbél the local population expressed their clear support in favour of people with disabilities who intend to move there in the future.

In this context, it is important to note that, although in some cases the protests by local population had a major stir in the media, applicant institutions make substantial efforts to inform and convince

the local population, to make them interested in the cause of deinstitutionalisation. From this viewpoint, institutions gain a positive role in that they are the largest employers in these communities. A head of one of the institutions pointed out sensitively that "the majority of the local residents either used to work, or are working, or will work in the institution." Hence, they have experiences with respect to the residents of the institutions and their living conditions that are mostly based on their own observations, or they know somebody working in the institution who they can ask their questions regarding deinstitutionalisation, thus fears and prejudices due to a lack of knowledge are less common among them.

In addition to informing the local population, there have also been positive examples of preparing the residents of the institutions. For example, in one applicant institution the residents of the institution are prepared in two steps. The first round includes only a small group of residents who are involved in protected employment. In the second step, the new groups are organized around cores composed of 2-3 residents prepared in the first round. With this method, professionals leading the small groups and the residents trained in the first round, by helping each other, together carry out the preparation of the rest of those affected.

The advocacy organisations of people with disabilities are represented in the IFKKOT by four people. Based on the interviews, on the whole, we received a mixed picture of this group. Disability advocacy organisations have shaped a strong position in favour of the idea of deinstitutionalisation, for it to be in line with the spirit of the CRPD. At the same time, a representative of the Hand in Hand Foundation believed that, as an intermediate solution, it was acceptable to reach during the preliminary opinion of the feasibility studies an informal agreement with the applicant institutions in that these applicants will not plan to establish institutions larger than for 30 residents in their proposals. Also, the position of the National Disability Council's representative was not entirely clear in relation to deinstitutionalisation. The NDC's representative showed a sense of attachment towards institutional care for a higher number of residents, as he considered the establishment of institutions for 50 residents acceptable. Thus, a mixed picture emerges in which some actors hold a strong position in favour of deinstitutionalisation to be implemented in accordance with the CRPD, while others still prefer to stick to the system and framework of institutional care that has been in place so far.

In the period which we examined, only two organisations which are themselves not members of the Board expressed their position on a regular basis. These were the Hungarian Civil Liberties Union (TASZ) and the Mental Disability Advocacy Centre (MDAC).

The two advocacy organisations which have been monitoring the process of deinstitutionalisation from outside expressed their clear position in favour of an uncompromising deinstitutionalisation in full compliance with the CRDP. It is particularly noteworthy that, in its position papers, the MDAC

found unacceptable not only the establishment of residential centres, but also that of group homes for 6-12 people. In their view, deinstitutionalisation in fact leads to the creation of new institutions in Hungary.

With respect to human rights organisations and advocacy organisations whose representatives we interviewed, the outcome shows a variety of positions. Ms. Csilla Szauer identified TASZ and MDAC as monitoring, Watch Dog actors.

The professional staff member of the Ministry of Human Resources, however, thought that the activities of these actors are rather a "mandatory expression of criticism in an unjustified manner."

Mr. János Wisinger formulated in an even stricter manner:

"The role of the Hungarian Civil Liberties Union is specifically harmful, because it uses such a generalizing, false, I would say spurious system of arguments which misinforms the public, and, unfortunately, the media and the politics shape their judgements based on this. MDAC is relatively realistic and attempts to represent the issues of the group which it protects on the basis of the EU and UN decrees. But this organisation, too, is slightly detached from the everyday life." (Mr. Wisinger, National Disability Council)

Ms. Csilla Szauer identified advocacy actors as active stakeholders with a critical approach, but ones with a positive, forward-looking initiatives.

"They are blocking in that they insist that institutions with a capacity of 50 beds should not be established, but in terms of the UN Convention, they are forward-looking." (Ms. Csilla Szauer, Public Foundation for Equal Opportunities for People with Disabilities)

This role was not seen by Mr. László Rubovszky as forward-looking even within the Board.

"I think that the presence of the Council of Organisations of People with Disabilities, as represented by an employee of the Hungarian Association for Persons with Intellectual Disability, sometimes unduly, as I see it, tried to curb the processes. (Mr. Rubovszky, National Association of Non-Governmental Organisation and Foundations for People with Intellectual Disabilities)

## 10. Interviews Carried out with Representatives of Institutions Participating in the First Round of Deinstitutionalisation

In addition to the opinions held by the members of the body coordinating deinstitutionalisation, we were also interested to know how, at the implementation points, the people in the institutions that were facing deinstitutionalisation related to the issue, and how they experienced the process of the proposal writing and preparation of deinstitutionalisation.

Of the six institutions which had submitted successful applications, we visited four institutions<sup>23</sup> and interviewed the staff of the institutions who had been involved in writing the proposal, and processed the results of the needs assessment carried out with the residents before writing the feasibility studies.

Since of the six applying institutions only four institutions participated in the preliminary preparation, and it was there that the pre-planned needs assessments were carried out, our interviews were made in the institutions located in these four settlements:

1. Szakoly
2. Berzence
3. Bélapátfalva
4. Szentés

### 10.1. Perception of Deinstitutionalisation in the Examined Institutions

As each institution applied for the funds to cover the costs of deinstitutionalisation, it can be clearly stated that the leadership of the examined institutions fundamentally supports the process of deinstitutionalisation and agrees with its objectives.

When asked what had inspired them to take part in the tender, the most common answer was to create more human and humane conditions:

"On the one hand, it is the crowdedness of the institution: we take care of 90 residents 24 hours a day. The level of crowdedness is high, which is not really in compliance with the legislation and the EU. I am referring here to the square metre per person. The institution is currently located in a listed building; it is, among others, a reason why it cannot be easily renovated; terribly much money would be needed to create the right conditions."

"What's most important is why we decided to get involved in this. In the past 10-15 years, whatever professional audit we have had, whatever professional inspection in the institution, each of these inspections or visits have confirmed that, on the one hand, this castle building is functionally unsuitable for performing the duties of a residential institution, and, on the other hand, those living conditions which you, too, will see are inhuman in the 21st century. So, living in wards of 8-10 12-15 beds in a social institution today is exactly what I have just said."

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<sup>23</sup> The following members of the research team participated in making the interviews and in processing the results of the needs assessment: Nóra Dezső, Nóra Szabó, Hajnalka Sátor, Anita Székely, Enikő Gargya, Attila Esztergályos and Zsuzsanna Kondor.

However, we also had an answer that referred to an outside inspiration, and we also had answers which suggested that the management of the institution recognized the need for a change of attitude in relation to deinstitutionalisation.

".. we had a visit of a woman named Glenna Michaela who used to be minister of welfare in the United States, in the state of Connecticut, as far back as president Carter's times. She made a couple of telephone calls and subsequently I met some people, among others Mr. Ákos Pordán He brought his Ph.D. thesis to discuss, possibly to talk about it. In a lot of things our professional tastes are alike with Ákos. We do have certain differences in opinion because I have the institutional practice, and due to my experience, to a certain extent my thinking is set. Still I have a full and absolute openness that can be mobilized for anything, again, to accept opinions, to try out things, we can take risks, just let's move on because we'll get stuck. There must be a change, a movement, there must be something new."

"And in my interpretation, if this programme succeeds, Hungary will demonstrate that it is not fascist, not racist, and that it can treat people with an unfortunate life in a completely fair way, thinking in a completely normal way. For me this is professional vanity, now that we are here among the first ones."

"Now, there is a mother-child relationship between them, and this will change. If it were up to me, we would want to take the full team of professionals to the new facility. And hire new personnel. Here we have nurses, there, in the supported living, we will have social workers"

## 10.2. Process of Planning - History

From part of the answers we could have an idea of how the heads of institutions felt involved in the process of policy planning, and what local and national movements accompanied their preparation for the tendering:

"In the past year and a half, our dear old ministry have not deal with anyone, even though we proposed ourselves that we are not enemies, but colleagues, it all was to no avail. Unfortunately, they don't negotiate with anyone. In my opinion this is a mistake, but they are the responsible ones."

"... then they invited me to a joint professional brainstorming. I said, listen, complete deinstitutionalisation is fine, but let's not destroy the values that have been created."

"I move around in professional circles quite a lot, and already then it was in the air that an EU call for applications shall be expected regarding the issue of deinstitutionalisation of large institutions. And because maintainers were those who had the possibility to submit these applications, we started to lobby with them, at that time it was the Somogy county institution

maintenance centre. Perhaps it is also part of the story that until 1 January 2011 we had been an institution maintained by the county.

In fact until 1 January 2012, but the reason why I said until 2011 is that in 2011 the County Council integrated us, merged us, and merged two other institutions to the Berzence institution, the Barcs home for people with disabilities with a capacity for 120 beds, and the Drávatamási home for people with disabilities with a capacity for 150 beds. This is how our institution became a gigantic institution caring for 510 residents.

Then came the nationalization which reached us in 2012; then we belonged to the Ministry of Public Administration and Justice, that is not to the Ministry of Human Resources, and it was then that the county maintainer centres were established. So this fourth maintainer centre was entitled, as a maintainer, to submit the applications, because that is how it was specified in the call for applications. So when we got wind of it, that this call for applications had been announced, we immediately contacted the maintainer and said that here is the possibility. Let's do it, for us this is the last chance."

### 10.3. Proposal Writing

We were also interested to know exactly how, under what circumstances was the proposal writing carried out.

In all the four places we managed to carry out interviews with those actors who themselves were actively engaged in writing the proposal, thus we were able to shape a rather suggestive idea of the process. Although today we know that each of the four institutions successfully handled the obstacles encountered during the proposal writing, it was not an easy period in their life.

"Writing the proposal was an interactive thing. I paid attention and gathered the information, it was not just writing it. We had coordination meetings until the middle of the night, trying to figure out whether a piece of furniture would be fine here or there, or not."

"That was most exhausting. You know, we are a small institution, we work off the 8-10 hours, and then we can deal with the proposal. What we could recommend to the future candidates is that it is important to solve the replacement of the professional staff in such a way that those who are engaged in the work do not split apart, but can concentrate on the proposal.

"The maintainer, I will teach the maintainer what all this is about, because they have been our maintainer for two years. They are extremely decent, nice people. My bosses are mostly professors of theology at universities, scientific people who speak many languages, but they do not understand the profession. And, sporadically, they accept those professional arguments, which I accept, well, because they see that it all works well."

The institutions were quite eager to turn towards the possibilities for consultation offered by the professional staff of the Public Foundation for Equal Opportunities for People with Disabilities (FSZK) and that of the National Coordinating Board for Deinstitutionalisation of Institutional Capacity (IFKKOT). Those were the events at which the Board successfully influenced also the plans related to residential centres.

"Once I was at the FSZK headquarters. Their help was based on their routine, and they have more of it than us."

IFKKOT's role of strong control is reflected also in the accounts of the authors of proposals:

"The first feasibility study we submitted was for 145 residents, IFKKOT rejected it. The call for applications specified that the residential units may not be each other's neighbours, but we thought that the social service centre is not a residential unit.

The residential centre could be built right next to the service centre, since if the goal is that during the day the residents should stay in the service centre, then, so to say, people with very high support needs can be taken from the residential centre to the service centre in no time.

IFKKOT said this was in violation of the principles, that the main point is that housing and services should be geographically separate, therefore we had to rewrite our second feasibility study."

We were specifically interested in what considerations were taken into account in writing the proposal about the selection of the future buildings, and in the course of this what role needs assessments played in it.

In many cases it was found that the primary consideration in the selection of property was the real estate portfolio at the disposal of the maintainer or the local / county government. This had primarily financial motivations, as, with this, costs can be reduced to the relevant degree:

"How did the property emerge? The Csongrád County Office of the Social and Child Protection DG has estates in Nagymágocs. There is no need to spend money on this there, all they need to do is just to manage the renovation and to buy two houses. And here in Szentes the local government offered plots. It was the value for money principle which decided whether to buy a real estate or to build a new one. A rehabilitation architect had to be involved."

"The designer guys came, a technical engineer was sent by the maintainer, I was there too, and then we started to look at the real estate buildings. There are a lot of houses for sale in the village, and, needless to say, several owners felt resentment over why it was not their house which had been chosen. But, let's say an existing attic bedroom flat in Berzence was certainly out of the question, because then an elevator for 12 million would need to be build

in. So here I really had to pay attention to what the budget allows, and what one can get out of an architectural reconstruction.

And the point is that we were able to find three real estate buildings, while, as I have mentioned, in fact it was about 11 real estate buildings. 3 flats with 3 bedroom, with six beds, 6 group homes which is a six-bedroom family house with 12 beds, this is a total of 90, and a 15-apartment residential centre for 30 residents whose needs for support are the highest."

So the issue of residential centres came up very quickly. Of the four interviewed candidates all, except BÉlapátfalva, made use of the opportunity of setting up residential centres, but in light of the compromises reached with IFKKOT, none of the candidates applied for residential centres with a capacity for 50 people. In any case, the following quote taken from an interview well illustrates the perception heads of institutions have about residential centres:

"Even now we have 8/10/12 residents who are in bed 24 hours a day. So, from now on, try hoisting them out of the bed in the mornings, taking them to the service centre where you will spend your days, and then hoisting them back home towards 4-5 PM.

So, the kind of idea imagined at the time by the body which announced the call for applications is good for people with real intellectual disabilities, but only that people with addictions and people with psycho-social disabilities were also included in this circle. And then it is important to know that in this type of institution there are people with very tough behavioral risks who require a higher level of supervision, as well as patients, in principle, of course, who need to be taken care of.

Thus, the residential centre was left in our project because, sort of, we can see from the experience of the past 50 or more years that when it comes to such a large group of people, 120-130 people, there are always 20-25 people whose health condition will require a 24 hour technical, that is physical care. That is what residential centres are for, nothing else. So we do not want to create a small institution within a large institution."

#### 10.4. Perception of the Needs Assessment

Although the representatives of the institutions agree with the importance of the needs assessment, in their judgement they believed they know their residents better.

"Waste of money. That's all. I do not want to hurt them because they were mostly my colleagues. Is it good in a place where there is no relationship of trust that we have. I know exactly the number of hairs everyone has. I know how many teeth they have, how many fillings and when they were made. Al right, it is in the programme, we accept it, we have been through it, it cost a lot of money for someone, but I judged it unnecessary."

"They came here once, they met on one occasion and filled in the questionnaire. We could not dissociate from the circumstance that we know them better. The conflict of views was in that we evaluated it differently."

Accordingly, it soon became clear that the needs assessment played a rather marginal role in writing the applications:

"I did not really use the needs assessment, but rather I used my own experience. I classified them by status, physical activity, and finally groups emerged: who goes to Mágocs, to Szentes, to a residential centre, or who can move to a separate flat."

"So my practical experience is that this money should be saved. It was my opinion that if an institution has a serious and committed team, not just on paper, but in reality, then this small professional team can prepare a professional development strategy for the institution, which in this case is deinstitutionalisation."

However, a very important argument, a need for the needs assessment was also voiced. One of our interviewees pointed out that these questionnaires recorded the residents' needs when they lived in a kind of a shell, and when, in relation to the outside world and life, they had minimal experience. A needs assessment cannot be as simple as a few hours or even days "spent here" by a team whose members ask a couple of questions, and then the results of it will make the basis for deinstitutionalisation.

Our research group processed on the spot the results of the documents of the needs assessment. In particular, we were interested, on the basis of the filled in assessment questionnaires, in the type of answers given by the residents in relation to their own future. Although the responses provided by our interviewees suggest rather that the answers are unreliable and impossible to evaluate, our colleagues who processed the fact sheets in the majority of cases found meaningful, often surprisingly specific responses:

"Would like to go back to Ópusztaszer where he lived for 17 years. Because there the service was better, just as the company and the caregivers. Would most like to stay in a double bedroom with Gabi K."

"Would like to live in one room with her friend, Györgyi M. Would like to cook in a group home, with a private bathroom which is not crowded. Would like a tape recorder in his room. Would like to have his teeth done."

"I do not feel good, we live in a separate building, I would like to do the housekeeping. I got married four years ago, but because of the institutional protocol we live separately."

"Would like a single-bed arrangement, a private TV, a radio, and own wheelchair to be able to sit in the park outside, in good weather in the fresh air, when he feels like it."

"She would like to live with her mother in Pusztakovácsi. He is a bachelor and would like to get married."

"Would like to live in small rooms with 2-3 people. Would like more civilized, more hygienic places (bathroom, toilet). Would move into a larger, more complex residential unit."

"Would like to live in Nyiregyháza with her friend Andrea K. and Anett H. and Katalin G. To do gardening, for example, to take care of flowers."

Among these specific, clearly comprehensible responses we found also answers where people preferred a possibly more cultured version of the institutional life:

"The current circumstances suit him very well, the services are adequate, also the degree of friendships. Hard to imagine anything else. Did not think about wishes, does not wish anything. Lives in a 6-bed room, but does not wish for a smaller one as the company is so good."

"Would move to an institution similar to the current one. Would like a single room."

The needs assessment in all four places took place in such a way that, apart from the colleagues carrying out the survey who arrived from outside, in addition to the residents those members of the personnel who were relevant from the point of view of the affected residents also participated. From the recorded responses and from their wording it turned out that those evolved from the interactions of the responses provided by the residents and the personnel. Sometimes the personnel's interpretation was stronger, on other occasions clearly the residents' own preferences emerged.

It is important to emphasize that, from among a total of 489 needs assessment sheets examined by us, in 334 ( 68.3 %) our staff found meaningful, specific answers similar to those quoted above. In comparison, only in 58 cases (11.8 %) our colleagues came across communicational absurdity, responses that are not possible to evaluate, lack of information. In the remaining cases, there were answers containing a few words, or those containing a few words written with help.

We cannot leave without a comment the discrepancy between how we see these needs assessment sheets and the answers contained therein, and their interpretation formulated in one interview:

"My dear, whoever has seen a living person with intellectual disabilities. Pistike! You would like to have a motley dog, wouldn't you? I would, father! And you wouldn't want to have motley dog, would you? Of course I wouldn't!"

## 11. Presentation of the Mentor Programme

This chapter of the study series which has, since January 2009, been following up the story of deinstitutionalising large institutions in Hungary presents one of the very interesting experiments of

2012 and 2013. The original objective of the Mentor Network providing support to deinstitutionalisation was to provide professional support necessary to implement a tender programme entitled Deinstitutionalisation of Residential Institutions Operational Programme (code number: TIOP - 3.4.1 -11/1). For this, the Hungarian decision-maker allocated funds from another Operational Programme whose project code number is TÁMOP 5.4.5-11/1<sup>24</sup>. The code stands for Social Renewal Operational Programme, the title of the project is Developing the Professional Knowledge in Removing Physical and Info-Communicational Obstacles

In our study we try to present the initial ideas professionals had in the framework of the project, namely the purpose and content with which the mentor network had been created. We will attempt also to present part of the implementation of the plans, although this, as we shall refer to it later, because of the delays in the implementation of the project and the related call for applications TIOP-3.4.1 can happen only on the level of making references.

In the course of the analytical work we examined the call for applications, the submitted feasibility studies (the text of which was used in several places where we presented individual commitments undertaken in the application) and the website which ensured publicity to some of the results: <http://www.hozzaferes.hu/tamop-545-111/mentorhalozat.html>. We had personal discussions with the professionals who were the creators of the project, with the professional leaders of the implementation and with the mentors as well. In the course of the preparatory work we examined the TIOP call for applications, and also tried to incorporate the experience of the on-site interviews carried out for another chapter of the research study. Also in the course of the preparatory work, we followed the professional series published by the Hungarian Civil Liberties Union on the subject of deinstitutionalisation<sup>25</sup>.

It is important to emphasize that the professional evaluation of the mentoring work is not among our goals! On the one hand, the process itself (implementation of TIOP applications) is far from being in a phase in which data suitable for a comprehensive analysis are available; on the other hand, at this point in time we would specifically like to provide a picture of the Hungarian professional framework; the operation related experience will be the subject of a forthcoming research study.

The application is implemented by the Public Foundation for Equal Opportunities for People with Disabilities (FSZK) and the Hand in Hand Foundation in a consortium-based cooperation. The FSZK (and its predecessor, the Opportunity of People with Disabilities Foundation) for more than ten years has been engaged in creating a barrier-free environment and has the professional and

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<sup>24</sup> The total budget for the entire project: 450 million HUF (<http://www.nfu.hu/doc/3289>)

<sup>25</sup> <http://tasz.hu/fogyatekos/tomegintezet>

methodological knowledge and experience which form the professional basis for the establishment of the support background (expert network) needed to create a barrier-free environment. The Executive Director of the FSZK is the president of the National Coordinating Board for Deinstitutionalisation of Institutional Capacity set up by the ministry. The consortium partner, the Hand in Hand Foundation was established in 1993 with the objective to provide support, on the country level, to people with intellectual disabilities, their family members, their caregivers and the non-governmental organisations working with them. In the project, the Foundation took responsibility primarily for the training related tasks, as well as for carrying out the situation assessment interviews.

## 12. Background

In the previous studies of our research series we demonstrated how Hungary had arrived at the initiative to allocate major EU resources for deinstitutionalisation. With respect to the development of the legal background which ensures support to and controls the process, the reader can receive a comprehensive description from a preceding chapter of this study.

These legislative changes and those on the level of regulations naturally had an impact also on the planning and elaboration of the professional concept of the TÁMOP mentoring programme.

The need to develop a mentor network is also specified in section 7 of Government Decision No. 1257/2011 (of July 21). The objective of establishing the mentor network is to provide professional support necessary to implement a project of the Social Infrastructure Operational Programme entitled Deinstitutionalisation of Residential Institutions (code number: TIOP - 3.4.1 -11/1). In the course of the design and implementation of their deinstitutionalisation programme, candidates implement mandatory ESF-type activities<sup>26</sup> as well:

1. Prepare the residents of the institutions for the changes that occur at deinstitutionalisation;
2. Prepare the personnel working in the institutions for the changes that occur at deinstitutionalisation;
3. Inform and prepare the living environment, with particular attention to the population of the affected settlements (areas);
4. Complex survey of the residents;
5. Organisational development.

The possibility of eliminating large institutions emerged in Hungary in the early 1990s. At that time it triggered heavy resistance, especially among the maintainers and the management of the institutions. Since then, the expansion of the human rights approach in the disability issue which took

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<sup>26</sup> Independent ESF (European Social Fund) type (e.g. training) support schemes cannot be launched in the framework of the ERDF (European Regional Development Fund). At the same time, the training activity can be supported in the framework of a project of essentially investment nature (ERDF) by taking into account the ESF related rules, but it may not exceed a maximum of 50 percent of the total eligible costs of the project. Another example may be that certain assets may become necessary in order to launch a training project, for which, observing the ERDF rules, it is possible to use up to 50 percent of the total eligible project costs. Interoperability is applicable if it is included in the given priority axis of the relevant operational programme; monitoring this and observing the priority level 10 percent (15 percent) threshold should be taken care of. Each activity must be accounted for in accordance with the eligibility rules of the main areas of intervention (Article 7(3) of the ERDF Regulation and Article 11(4) of the ESF Regulation. In other words, if an OP project financed by the ERDF is funding an ESF-type activity (e.g. training), the eligibility rules of the ESF Regulation ( Article 11) apply. (Source: ERDF General Guide to the eligible costs for the 2007-2013 programming period, and the ERDF General Guide to the eligible costs for the 2007-2013 programming period; [www.nfu.hu](http://www.nfu.hu))

place in the past nearly twenty years has brought significant changes to the professional and policy environment in which deinstitutionalisation of institutional capacity is a subject. By today, the professional way of thinking has significantly changed, in fact, the state which is the maintainer of institutions also shows a much stronger will in its government decision to deinstitutionalise<sup>27</sup>.

The transformation of large residential institutions and the establishment and operation of a new organisational and infrastructural framework is expected to be a long and difficult task for the Hungarian institutions, therefore, it is particularly important that all the stakeholders receive adequate support, as a candidate wrote in the feasibility study. In changing the several decades' practice and in developing an entirely new mode of operation, making a prepared group of experts (mentors) of a complex composition available was a very important element in providing support for the applicants of the TIOP call for applications (and for those who implement the tender). The professional support had to cover a number of areas, hence the Project of the Social Renewal Operational Programme undertook, in deinstitutionalisation of institutional capacity, to support the residents of the institutions, their family members, professional personnel working in them as well as the new host environment by providing mentors.

In relation to deinstitutionalisation, a head nurse drew our attention to the loss of control, saying that until now "there has been order" in the institution, but if the residents start to live an independent life, it will be difficult to control the patients

It was striking to me that both the personnel and the residents suffer from a lack of information. When I personally interviewed one resident who had no awareness of illness, the resident asked what would happen to them in the future, saying "surely we don't have to leave Szentes, do we?", then inquired who he would be placed with and in what circumstances. So the residents are aware that their life will change, completely, but the uncertainty was tangible. I believe it is the lack of information that strains the residents most. Staff members are also torn between doubts, it is their normal rhythm of life and their workplace which will change dramatically. One staff member said that "There will be something, we may just go and hold sessions at the new centre." (excerpt from an interview)

The basis of the mentor programme design was the presumption that neither the institutional transformation, nor the full barrier-free infrastructural investment or preparation of the human

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<sup>27</sup> Government decision No. 1257/2011 (of July 21)

resources can be implemented by a candidate institution in-house on the level of the host environment, personnel, or the residents.

Assistance provided in the writing of the Social Infrastructure Operational Programme application was also to be among the tasks of the mentor network, but because of the delays in the two tender programmes this eventually did not materialize: when the institutions had to elaborate the TIOP applications, the tendering process of the TÁMOP had not been complete yet, that is, the mentors had not been in place.

	TIOP-3.4.1.A-11/1	TÁMOP-5.4.5-11/1
call for applications announced	27 January 2012	10 January 2012
Deadline for submission of applications	1 June - 31 August 2012 → Changes were made here, see the footnote <sup>28</sup>	19 January - 10 February 2012 amendment: 19 January - 20 February 2012
decision on the winning tender(s)	Phase I: March 2013 (4) Phase II: June 2013 (2)	14 June 2012
contract(s) concluded with the successful candidate(s)	First contract in force: 12 August 2013	12 July 2012
project implementation phase	this varies greatly, but certainly the applications need to be completed by no later than 30 June 2015 (which is less than two years! Given the complexity of the projects, it is quite little time!)	15 February 2012 - 14 February 2014 (it is doubtful how mentor support can be present in the second phase of the TIOP project implementation!)

The data in the table above show that the effort to harmonize the tendering process of two, in principle interdependent, projects to meet professional expectations failed. The mentoring programme should have been ready and "waiting" for those who intended to enter the TIOP competition to enable the expert group to support the work from the very beginning. This would have been fortunate also (and we will refer to this later) because the preparation of, planning and writing the TIOP project is fundamentally a serious and complex work process which carries (may

<sup>28</sup> Based on the provisions of the Guideline of 3 May 2012: The time frame for the submission of applications was between 1 July 2012 and 1 October 2012, and the submission and evaluation of an applications occurred within one stage.

Based on the provisions of the Guideline of 21 September 2012: Applications can be submitted until 5 November 2012.

Based on the provisions of the Guideline of 31 October 2012, the application deadlines changed again: Phase I: From 1 June 2012 until 5 November 2012 Phase II: possible from 17 December 2012 until 15 February 2013. Submission and evaluation of applications takes place in two phases.

Based on the provisions of the Guideline of 19 November 2012, the application deadlines changed again: Phase I: From 1 June 2012 until 5 November 2012 Phase II: possible from 1 January 2013 until 15 February 2013. Submission and evaluation of applications takes place in two phases. A further change was that, in the second round, the Feasibility studies of the applications had to be submitted for approval to the IFKKOT electronically and by post no later than 30 November 2012. The IFKKOT issued its statements to the applicants until December 27.

carry) all those numerous internal organisational and human conflicts and uncertainties, and handling these can (would have been) truly effective and efficient if there is trust between the cooperating parties. For developing this trust a very good interface is (would have been) to follow through and support the difficulties of preparing the application. Failure to do so later raised trust related problems in several places. Handling these problems was of course possible, but a better designed (more flexible?) application process could have helped avoid these "extra goes". The calls were announced almost at the same time; this determined that the preparation of mentors would not happen by the time of the launch of the TIOP applications.

A further unfortunate aspect of this time issue was that the decisions on the TIOP tenders were made much later than what anyone had expected, thus the initial "set of handicaps" was further boosted by the circumstance that the trained mentors were waiting for almost a whole year for a decision to be made on where and with whom they would be working. The main applicant, the Public Foundation for Equal Opportunities for People with Disabilities initiated the extension of the TÁMOP project financing mentoring support, however, at the time of closing our study no decision had been made. To summarize, compared to the initial professional concepts, expert support for the deinstitutionalisation task will be provided in a much narrower time interval.

Milestones of the TIOP project	Preparation for the proposal writing	Preparing the proposals	Making possible changes, finalizing	Process of concluding the contract	Preparation for the implementation	Implementation	Closing
Participation in the TÁMOP tender	No mentor support	No mentor support	No mentor support	Start of the mentoring activity	Start of the mentoring activity	the mentoring work is already partly financed from the TIOP tender	the mentoring work is financed from the TIOP tender

### 13. Tasks Undertaken in the TÁMOP (Mentor) Competition

#### 13. 1. Establishing and Operating the Circle of Counsellors

Among the tasks undertaken in the TÁMOP competition, one of the first tasks scheduled to be implemented would have been to find a 40-person circle of counsellors who would have provided professional guidance in the proposal writing stage for those institutions which were engaged in the TIOP-3.4.1-11/1 competition. This guidance was to be provided in the following three areas:

- a) Assessment of the need for complex support,
- b) Coordination of the assessment team,

c) Property assessment and transformation.

In accordance with the applicants' plans, the counselling professionals engaged in the preparation of the mentor network would have participated, following the preparation, in the assessment of the complex support needs of the affected people living in institutions with a capacity for 1,500 people, as defined in Act XXVI of 1998.

The results were: Between March and July 2012, a survey of 1,103 people in a total of nine institutions was carried out. In each case, the survey documentation was left in the institution, since it had been made for them in order to enable them to prepare for the deinstitutionalisation competition. There were two institutions in which originally there was no counselling because they had not asked for it, but eventually they submitted their application and, in the revision period, the survey of additional 250 people was carried out, but it was carried out by the personnel of the institution with the assessment tool which was used in the project as well, following a quick preparation. The details of the survey are presented in Chapter 10.4 of this study.

### 13. 2. Mentor Network Management Team (MNMT)

Based on the project plan, the establishment and operation of the new professional network is managed and supported by a new professional body which is represented by the major actors of the professional field, as well as by advocacy organisations concerned. The body was designed to consist of 8 people: a representative of the Ministry of National Resources, one from the Special Education Faculty of ELTE named after Gusztáv Bárczi, one from the Hand in Hand Foundation, one from the Public Foundation for Equal Opportunities for People with Disabilities, as well as two representatives from advocacy organisations of people with mental health problems and people with addictions, and from the Council of Organisations of People with Disabilities. This team composed of leading experts was responsible for: elaborating the conditions for establishing the network of mentors, the order of operating the network and content of the training programme for mentors, as well as developing the modus operandi of their activity and monitoring its implementation. The Mentor Network Management Team was designed to operate as a team providing professional support to the work of the National Coordinating Board for Deinstitutionalisation of Institutional Capacity. MNMT's operation is currently very formal in nature. It did not play a major role in the selection of candidate mentors and in developing the operating system of the mentor network.

### 13. 3. Training Programme and Events Related to the Mentor Network

The TÁMOP project envisaged significant resources for the training programme to be organised for members of the mentor network. This process was to ensure that well-prepared mentors who are ready to co-operate are available for each momentum of the extremely complex transformation process which requires a variety of professional skills. Implementation of the accredited training programme was carried out in autumn 2012 (see Annex 1).

For those mentors who successfully completed the training, professional workshops were planned to be organized with a view to activate their skills on a practical level before the activity begins. These workshops took place from January through March 2013 (internal memos were issued on them); these workshops were about developing the operational procedures of the mentor network and about creating a framework for the actual work.

The FSZK scheduled two "mentor meetings" in the project plan as well: to ensure space and opportunity for each member of the 100-strong team of mentors so that they meet each other, learn about each other's activities and share experiences. The first mentor meeting will be held on 3 October 2013, while the second one will be held at the end of the project (expectedly in May 2014).

### 13.4. Finding Mentors

In order to engage 100 main mentors, there was a need for a serious procurement procedure which FSZK, as the main applicant, conducted in the summer of 2012. The mentors selected in the course of the procedure were planned to be outsourced to those institutions which were successful TIOP candidates.

In addition to the planned and realised time frame, the table below shows also the large variety of mentoring groups recommended by the project for the TIOP candidates. In accordance with the complexity of the deinstitutionalisation process, starting off from the organisational issues through the personal support and taking into consideration the training and employment areas, the creators of the competition made an effort to compile a diverse range of expert support. However, referring back to our earlier critical observation, it is important to indicate that in order to introduce such a large support team there is a need for sufficient time! By imagining ourselves in the position of the TIOP candidates it is easy to understand that, after the proposal writing period fought through in an almost solitary way, an 8-10 strong mentor team can be received with some scepticism as to exactly who, what and how will offer real help to them!

	PLAN	PLAN	FACT (data of September 2013)	FACT (data of September 2013)
Mentor group name	Time of operation	Period of monitoring the process	Time of operation	Period of monitoring the process
1. supporting heads of institutions	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
2. Strategic professional	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
3. Institutional transformational	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
4. Institutional operational mentor group (HR, law, economics)	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
5. Rehabilitation engineers	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
6. Supervisor-coach	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
7. Employment	January 2013 - January 2014	January 2013 - January 2014	from June 2013 onwards	April 2013 - December 2013
8. Training mentor group	January 2013 - January 2014	not necessary	from June 2013 onwards	April 2013 - December 2013
9. Those making complex support needs assessment	October-November 2012	October-November 2012	was not implemented	-
	May-June 2013	May-June 2013	August-September 2013	April 2013 - December 2013
	October-November 2013	October-November 2013	is expected to be implemented	

In the course of planning mentors' capacity, the applicant FSZK planned it so that if competition TIOP-3.4.1-11/1 results in at least six winner institutions, it will ensure 300 mentor days of support per individual institution. The planning can be considered successful in that exactly six institutions won support. In the meantime, instead of mentoring days the FSZK specified mentoring hours, and it plans to share these among the winning organisations as follows:

Institution (Maintainer)	Mentoring time frame until 31 January 2014 (source: TÁMOP-5.4.5-11/1 priority project)	Mentoring time frame until 1 February 2014 (source: TIOP-3.4.1-11/1 competition)
Berzence (Social and Child Protection Directorate-General)	1,272 hours*	1,196 hours
Bélapátfalva (Social and Child Protection Directorate-General)	1,272 hours	1,196 hours
Kalocsa (city)	575 hours	895 hours
Mérk (Social and Child Protection Directorate-General)	825 hours	1,400 hours
Szakoly (Greek Catholic Church)	1,272 hours	1,196 hours
Szentes (Social and Child Protection Directorate-General)	1,272 hours	1,046 hours

\*to provide a little help, the above number can be converted, counting by 6 hours, into 212 person/days, which for the 8 different mentors is nearly an average frame of 26.5 days.

### 13.5. Monitoring the Process of Mentoring Activity and Quality Assurance of the Mentoring Process

For each mentor group it was planned to provide the opportunity of regular meetings moderated by a leadership expert. A double objective was identified for the meetings: on the one hand, to provide consultation opportunities for expert mentors in professional issues, and, on the other hand, to develop joint proposals for resolving the pitfalls of mentoring activities. Internal reports were written on the meetings. We were informed by the representative of the FSZK that processing of documents will be implemented during the preparation of the methodological guide.

### 13.6. Maintenance

As in any EU project, there is a major issue related to the planning of maintenance. In connection with establishing a network of mentors, in accordance with the requirements set in the guide for applicants, the project owner made the following commitments:

- to ensure the availability of accredited mentor training for those wishing to participate,
- to provide the opportunity for institutions to make use of the mentors who have completed the training (to the extent of the capacity)
- to make the teaching materials of the mentor training available free of charge to everyone
- to conduct annual reviews and evaluation of the mentor training,
- to coordinate the activities of the mentoring network, to annually evaluate and review its functioning
- to provide the opportunity for mentors for regular group consultation which assists their development.

At the time of completion of our study, the professional and substantive issues of the mentoring programme were hardly possible to examine, but in a future research task it will be worth examining the results of the first cycle of the tender and analysing the concrete experience of their implementation.

## 14. Summary

Having been monitoring the process of deinstitutionalising institutional capacity in Hungary already for four years, we can conclude without the slightest touch of doubt that the process of deinstitutionalisation in Hungary has arrived in the implementation phase.

Co-financed by the European Union's Structural Funds and Hungary's central budget, in the first step which will last for three years, approximately 700 beds of six large institutions will be deinstitutionalised. The legitimacy of the process is backed by the UN Disability Convention which has been ratified by Hungary, the Deinstitutionalisation Strategy which was elaborated along these lines, as well as the fact that, with the objective to support deinstitutionalisation, the relevant domestic legislation had been amended already before the concrete start of the process.

However, this legal framework was elaborated in a way that was not acceptable for all participants. What remains highly controversial is authorisation for the creation of institutions with a capacity for 50 people in the Hungarian legislation, and, unfortunately, the issue of legal capacity of persons has not been settled yet either.

The attitude of individual policy actors towards the issue of deinstitutionalisation is fairly dissimilar, but both on the level of political decision-making, as well as on that of implementation, so far it has been possible to mobilize sufficient support for the proposed changes to make them start off. With respect to the nature and the content related elements of deinstitutionalisation, however, frequently heavy debates accompany the process. Despite the international recommendations and the criticism on the domestic level, the Hungarian decision-makers insisted on establishing institutions with a capacity for 50 people, nevertheless, in a peculiar way, these institutions in practice - at least in the current first stage of deinstitutionalisation - are created for a much smaller number of residents.

Compared to the conditions set in the legislation and the call for applications, a progressive change occurred primarily as a result of the activities pursued by the National Coordinating Board for Deinstitutionalisation of Institutional Capacity (IFKKOT). The Board played an important role in the preparations of the implementation of deinstitutionalisation and in the actual execution of the application process. A condition for the evaluation was the statement of support issued by IFKOTT which gave a real possibility for the experts of the body to shape the content of the applications. Unfortunately, in the future this possibility will be present in a much more limited way, as after the formal submission the applications will be managed by the National Development Agency, and IFKOTT will no longer have a real, official possibility to influence their content. Although, based on its name and its charter of foundation this body is authorised to implement the co-ordination of the Deinstitutionalisation Strategy intended for a 30-year time span, by the third year of its activity the IFKOTT lost the possibility of control over the pending applications and did not have even a minimal say in the use of the future EU funds.

This is despite the fact that in the past two years, in addition to its formal role, the Board made a major step forward in bringing about collaboration among various policy actors and in creating a discourse in which the positions of the representatives participating along very different interests and motivations could get closer to each other. We believe that this is such a positive development

of the process of deinstitutionalisation which, in the long term, could help develop a decision-making culture in Hungary which is much more based on policy dialogue and consensus.

For the time being, this is contradicted by the current, rather introverted decision-making mechanism, which is seen as such also by the actors we interviewed. The real decision-makers of the sector did not participate at the staff meetings of IFKOTT, similarly to the representatives of the institutions implementing deinstitutionalisation and those of the civil and human rights organisations which monitor the process from outside who were left out. In our experience, currently there are still serious obstacles to bringing all the above actors to one table. So while the IFKOTT has produced indisputable achievements on the level of policy actors in shaping the decision-making culture based on discourse, we still cannot say that a comprehensive, professional discourse in the issue - which is otherwise an important condition in the policy recommendations - involving all stakeholders has been put in place in Hungary.

On the part of applicants, a concrete commitment is detectable in relation to deinstitutionalisation. This is despite the circumstance that virtually they have to eliminate their own institutions (their jobs) which they have operated for decades. Although the four institutions we interviewed did take part in the consultations provided by the FSZK and the IFKOT, and there they also received relevant support, they still experienced the tendering process as an extraordinary burden, and this is probably what they shall expect during the implementation as well.

Although in the TÁMOP programme, which is examined in the present study in detail, significant resources are available to secure professional support in the process of deinstitutionalisation, because of the design / tendering / conclusion of contracts related delays of the TÁMOP-TIOP proposals, the mentor programme created for this purpose could not provide real support in the proposal writing process. Their more active presence can be expected in the implementation phase, however, this will not happen without tension:

"This over-secured idiocy, I had nothing against all that, in fact I was glad that mentors were coming. But it makes all this costly, there are too many of them. And I don't see that they know exactly what help so many people here are going to provide. So they don't have enough local knowledge. One has to be very careful when saying that they would go to an institution as a mentor. One can know the inner life of the institution only by living in it. But where and how - I do not see it yet." (excerpt from an interview about the involvement of mentors)

"Charming, nice people, they understand the profession, in fact, they will help with their advice indeed, they are already helping, not me, but my bosses to accept what I say! So, the lack of trust. Those who announced the call for applications have no idea what they have

announced it for. They are smart, very great knowledge, but this is a specialized area of expertise." (excerpt from an interview about the involvement of mentors)

The needs assessment process was accompanied by serious preparations, nevertheless, its implementation did not live up to the expectations. Although the needs assessment sheets had been completed for each affected individual, the elaboration of the applications was not based on the the results of these sheets, that is, not along the needs formulated by the stakeholders. This seems especially acute in relation to the selection of the future properties. In it, a much more significant role was played by the portfolio of available real estate buildings managed by the maintaining local governments, or the local real estate lobby which, in many cases, was burdened with conflicts, rather than the stakeholders' preferences related to housing. In our view, this practice must definitely be changed in the future applications.

At the same time, both the needs assessment and the mentoring activity can trigger a major change in the Hungarian professional culture if, despite the initial failures, it will finally become possible to link the activities of the different actors on a track that is multiply burdened with difficulties. We believe that the success of the deinstitutionalisation programme can be assured mostly through the co-operation of all stakeholders of the professional palette ranging from policy makers to those affected. By casting the burden of responsibility only on the institutions, the process cannot be successful.

## Annex 1

Details of the training programme<sup>29</sup>:

The course title: Training of Mentors Supporting Deinstitutionalisation of Institutional Capacity (50 hours). The objective of the training was to ensure that participants become prepared to provide professional support needed to implement TIOP tenders.

The Training of Mentors Supporting Deinstitutionalisation of Institutional Capacity (TMSDIC) consisted of five modules:

1. International models and experience in the light of the Hungarian process of deinstitutionalisation
  - International models in the process of deinstitutionalisation
  - Identifying best practices
  - Using the same system of concepts with the other participants in the process of deinstitutionalisation
  - Awareness in the process of deinstitutionalisation
  - Significance and function of organisations providing services in the deinstitutionalisation process, the key factors of the area
2. Transformation of institutions/organisations and training of the personnel
  - Main elements in ensuring the quality of life
  - Recognizing the links between supported living and quality of life
  - Making the different forms of living suitable for the needs of people with disabilities
  - Adjusting forms of living to the needs of people with mental health problems
  - Making the different forms of living suitable for the needs of people with addictions
  - Learning skills of providing support which are necessary in the transformation process
3. Making use of supported living related services - principles and core values
  - Structure and function of the TMSDIC mentor network
  - Exploiting the opportunities contained in the operation of the TMSDIC mentor network
  - Advantages of decentralised organisational structures
  - Key points of developing decentralised organisational structures
  - Results of support related needs assessments
  - Forms of employment and opportunities for people with disabilities
4. Mentors' tasks, activities and planning of the mentoring process, and determining the modalities of cooperation

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<sup>29</sup> the training related background materials, presentations and the results of activities held at workshops are available at: <http://www.hozzaferes.hu/tamop-545-111/mentorhalozat/mentorkepzes.html>

- Individual mentor types, their role and tasks
- Defining one's own mentor type, outlining the functions and roles
- Presenting one's own activity

5. Key mentors and workshops of the expert mentor groups which determine and develop the methodology, literature and operational direction of the given area of expertise.

- Tasks of individual mentor types
- Timing the tasks of individual mentor types
- Formulating questions related to the operation of other mentor groups
- Creating one's own schedule of tasks

In accordance with the accreditation, exemption from module 4-5 could not have been granted.