

Ágnes Kozma – Gábor Petri – Attila Balogh – Magdi BIRTHA

*The role of EU funding  
in deinstitutionalisation (DI)  
in Hungary and the experiences  
of the DI programme so far*

Executive summary

2016.

The aim of the present research is to provide information and expand knowledge of advocacy work in the 2014–2020 programming period in regards to the EU and the Hungarian government.<sup>1</sup>

The research studies four main questions:

- 1 *The appropriateness of programmes:* to what extent investments in deinstitutionalisation and community living have been in line with the EU's funding priorities (social inclusion and anti-discrimination) and the provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD) in the 2007–2013 programming period;
- 2 *The appropriateness of projects:* whether the projects that received funding were in line with the UN CRPD;
- 3 *The effectiveness of organisations and systems:* how effective the organisations responsible for managing EU funds in Hungary have been in terms of setting and implementing strategic objectives and allocating funding;
- 4 *The appropriateness of planning:* to what extent planning and preparatory work for the 2014–2020 programming period can be considered successful.

In order to answer these questions, we carried out three thematically and methodologically distinct studies.

Study 1 discusses whether EU funding in the 2007–2013 programming period is facilitating deinstitutionalisation (DI) and the development of community living in Hungary by structured analysis of publicly available documents and information obtained from the relevant organisations, as well as interviews with stakeholders. Study 2 analyses the experiences of the implementation of the six DI projects. Study 3 focuses on the narrative of persons with disabilities who are moving out of the institutions as a result of the DI projects.

---

<sup>1</sup> The research was carried out between December 2014 and March 2016, commissioned by the Hungarian Civil Liberties Union and financed by the Open Society Foundations (contract number: OR2014-12493).

## Deinstitutionalisation in the 2007–2013 programming period

In the four Operational Programmes (OP) that were analysed the modernisation of institutions was identified as the main objective. Despite mentioning ‘deinstitutionalisation’ as a primary goal in all OPs, the text of the programmes did not guarantee that only investments that actually support the closing of institutions will be financed through the programmes. Even the project indicators were only targeted to measure only the level of modernisation and development (which may have included deinstitutionalisation), but there were no specific indicators, or benchmarks on DI. This shows the lack of commitment of both the Hungarian government (which at that time has not yet ratified the UN CRPD) and the European Commission (EC), as the OPs need to be approved by the Commission.

Yet, between 2007–2013 the Hungarian government financed a number of projects that certainly contributed to the implementation of the provisions under Article 19 of the UN CRPD. Such projects were carried out in the areas of employment, accessibility, independent living of persons with visual and physical impairments, or providing persons on the Autism spectrum and their families with education, health and social support services. In the programming period 2007–2013, a minimum of HUF 13.7 billion was spent on such projects, relating to persons with disabilities. However, 40% of the total funding supported large scale institutions, simply because the beneficiaries were such institutions (e.g. Rehabilitation Centre for Persons with Physical Impairments, National Institute of Blind People).

We have conducted 15 semi-structured interviews with professionals who were involved in the planning and implementation of the projects.<sup>2</sup> Based on the interviews, it is clear that the UN CRPD and the distribution of EU funding presented a challenge for the Hungarian public administration and for the social and disability policy sector as well. This period – after 2007 – is therefore to be considered as a learning process to introduce a fundamentally new practice for financial distribution that can contribute to formulating new policies.

---

<sup>2</sup> Despite our intention, it was not possible to include in the research the Directorate General of Social Affairs and Child Protection (SZGYF) that plays a central role in the DI as the managing authority for most institutions since 2012. The SZGYF refused to collaborate with our research project.

It seems that during the programming period 2007–2013, the UN CRPD was known and considered to be a framework for both European Commission officials and Hungarian stakeholders, including public administration and civil society. However, all of these stakeholders considered it a framework, rather than a guideline to be followed. The representative organisations of persons with disabilities (DPOs) were often not involved in the planning and implementation process. Although there were civil society representatives in the Monitoring Committees of the OPs, their role - for structural reasons - was indeed very limited.

The role of the National Committee for the Coordination of the Replacement of Institutions (in Hungarian: Intézményi Férőhely Kiváltást Koordináló Országos Testület or IFKKOT for short) was discussed by many of the interviewees, however the Committee emerged as a body lacking both resources and the necessary a mandate to be a strong actor in the DI process. Despite the formal involvement of DPOs, it is also unclear how persons with disabilities who are currently living in institutions are represented on the Committee. Almost all respondents suggested strengthening the Committee's role in the DI process.

The development of inclusive mainstream services and the interest of local communities were highlighted in a number of interviews, but the Hungarian DI strategy does not offer any solution to those concerns. Regardless, the closure of institutions is not part of a comprehensive reform strategy that would challenge the circumstances which have perpetuated the institutionalisation of persons with disabilities, but rather has been a piecemeal process. This raises serious concerns about the potential for re-institutionalisation in the newly established supported living facilities. This problem is recognised by public and civil stakeholders, yet nobody mentioned a possible solution.

Inter-institutional relations among key actors are rather bad: lacking mutual trust and a willingness to cooperate. This general lack of trust is somewhat compensated by existing and constructive inter-personal connections. Bureaucratic barriers (such as public procurement and the creation of a single national agency in 2013 to manage all state-provided residential services) negatively affected both the planning and implementation of DI projects.

## DI policies in the programming period 2014–2020

Projects funded for the 2014–2020 programming period have not yet started during the research period, and therefore our results are based on an analysis of provisional documents and interviews with relevant professionals.

One of the key areas of the Partnership Agreement that relates to persons with disabilities is de-institutionalisation. Therefore, the 2014–2020 programming period presents a great improvement in terms of its content and objectives compared to the previous period. However, the administrative framework to apply for EU funding is more complicated than before. Interviewees reported that already in the 2007–2013 period, administration presented one of the greatest impediments to their work.

## Experiences of the DI process in the 2007–13 programming period through assessment of the content of the projects and the framework for implementation

In early 2012, the Hungarian Development Agency launched the project call ‘TIOP 3.4.1.-A-11/1’ for applications that aim to close down large scale residential and psychiatric institutions. Through this process, six institutions were selected for the deinstitutionalisation of about 700 persons. Our aim was to assess the implementation process, with special regard to addressing the positive and negative aspects of the process. We relied on three main sources of information: the implementation plans, final reports and other relevant documents; field trips and interviewing the management of the institutions<sup>3</sup>; interviews with other stakeholders.

As regards the implementation of the UN CRPD, it raises concerns that the implementation plans included the establishment of so-called ‘Residential centres’ that can accommodate up to 25–30 people, while placing only a minority of the residents in flats. It is important to note that at the end only 672 people out of the 770 who lived in the six institutions moved out, and thus the DI process remains incomplete. Unfortunately, there are still residents, primarily older people with intellectual disabilities who remain in institutional care.

The ‘mentor programme’ was a unique element in the Hungarian DI process: its primary aim was to provide professional support and guidance to institutions by making available a pool of experts (mentors) in a range of areas (including needs assessment, employment, training, universal design etc.). Institutions implementing DI projects were required to use mentorship, although mentors had virtually no powers in the actual implementation of projects. We have carried out a number of interviews with mentors, and they all considered mentoring as an important element in deinstitutionalisation. However, the training of mentors and the allocation of mentors to the specific institutions were rather controversial. At the beginning of the project, the institutional staff did not believe that mentors could be helpful during preparation for DI, but eventually their relationship improved. A number of interviewees highlighted that the allocation of time for each mentor to spend in the institution did not correspond to the required workload which resulted in limited successes. The people that we interviewed knew very little about the adequacy or the quality of the training that was provided to the institutional staff due to the nature of public procurement through which they were selected.

---

<sup>3</sup> During the development of the research methodology, our initial aim was to visit all six institutions that participated in the DI programme to include their experiences in the study. In the end, we could visit only two institutions as four institutions refused to take part in the research. They also declined to provide us any information about the on-going projects.

There was a lack of coordination in the DI process, as no other organisation stood up as a coordinator, besides the limited role that the IFKKOT played. The creation of the mentor system without strong coordination or oversight further complicated the DI process, because the Equal Opportunities of Persons with Disabilities Non-profit Ltd (FSZK) and the Ministry effectively relinquished their control and played an inactive role. In the next programming period, the role of the mentors and their place in the whole DI process requires fundamental revision, with special regard to the selection of mentors and the content of the training they receive.

Similarly, advocacy and self-advocacy in the DI process also need to be reviewed in order to ensure the active and meaningful involvement of the representative organisations of persons with disabilities in the next programming period.

The efficiency of staff preparation is questionable, as it happens long before the actual DI would take place without any further supervision or follow-up. In the projects, more traditional, theory-based trainings took place, however it would be necessary to provide staff with more practical information, tailor-made to their current knowledge and future needs.

## The involvement of the residents of the institutions in the DI process

The involvement of the residents in the DI process happened through two main channels: On the one hand by preparing them to move out and begin independent living, and on the other hand through involvement in important decisions relating to project implementation. According to the data, there is no person-centred planning tool available to ensure the meaningful involvement of all persons who were affected by the projects – the complex needs assessment tool is far too limited for this role.

Most persons with intellectual, or psychosocial disabilities who are living in institutions are deprived of their legal capacity and are placed under guardianship. This means that they have limited opportunity to make their own decisions. We are concerned that without the revision of their legal capacity status and the development of a supported decision-making model, persons who move out of the institutions will not be able to enjoy real independence. It seems absolutely necessary to carry out a complete revision of the Hungarian legal capacity legislation.

Future projects which prepare people to move out from an institution require more attention to person-centred planning and an individualised approach. Since there are no universal solutions on how to prepare someone for independent living, calls for accredited training programmes for people with disabilities are controversial. In theory, the projects wanted to make people 'capable' to live independently with as little support as possible, and further determined the potential success of the projects on the basis of the individual's ability to be independent. This approach completely misinterprets the concept of independent living and supported living. In reality, anyone can live independently using as much, or as little support as it is necessary, depending on the individuals' skills and abilities.

In order to explore the experiences of persons with disabilities who were affected by the replacement of large institutions with smaller homes, we used Photovoice, a participatory research method. The core of the method is that participants create photo documentation in order to explain fundamental changes in their lives that otherwise would be difficult to share by using merely verbal communication (e.g. during the interviews). The institution in Szakoly (Szent Lukács Szeretetszolgálat) agreed to take part in the photo project between October 2015 and February 2016. The seven participants took about 500 photographs that can be categorised as follows:

- (a) Photos relating to events in the institution (Christmas, New Year's Eve, Carnival);
- (b) Photos relating to everyday life (work, free time and hobbies, friends);
- (c) Photos relating to the preparation for moving out of the institution (packing, visiting future homes, fellow residents, following the construction of new home);

According to the photos and the information that the residents shared with us, it seems that they took active part in the process and were looking forward to moving out.<sup>4</sup> The people who took part in this project could decide with whom they wanted to live with from among the population of the institution, but it was not a simple decision. Participants also had a say about the colour of the room, but furniture was purchased through public procurement. Those who have personal belongings, including furniture can take them to the new apartments to make the space more personal.

The interviews with residents confirmed that they mostly expected improvement in the quality of their living arrangements, but also hoped for further improvements in their quality of life after moving to smaller group homes, or flats. This includes a more relaxing environment, more security, and or less conflict with fellow residents.

---

4 We know from the mentor interviews that this was not the case in other institutions.



The full report (in Hungarian) can be downloaded from here:  
[http://ataszjelenti.blog.hu/2016/05/07/unios\\_forrasok\\_es\\_a\\_fogyatekosugy](http://ataszjelenti.blog.hu/2016/05/07/unios_forrasok_es_a_fogyatekosugy)

TASZ  
TÁRSASÁG A SZABADSÁGJOGOKÉRT  
KÖZHASZNÚ EGYESÜLET

1136 BUDAPEST, TÁTRA UTCA 15/B.  
TELEFON +36 1 209 0046  
FAX +36 1 279 0755  
[www.tasz.hu](http://www.tasz.hu)