



Deinstitutionalisation in Hungary Frequently Asked Questions

Publication date:

26 February 2018

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1. Why is it a problem that people with disabilities are living in large institutions?

The basic idea of institutionalising people with disabilities is wrong. We cannot speak of a 'good institution', even if all the staff are well-intentioned and enthusiastic, the landscape surrounding the institution is beautiful, the building has been renovated and there are lovely paintings hang on the walls. Institutions are, by definition, built to separate people from the community, and control the behaviour of the residents. Living in an institution denies people their freedom and their individuality. In many cases, institutions operate as isolated communities in border areas, in no-one's land. People with disabilities live in isolation from the rest of the society, often against their will. Institutions are usually crowded and closed, and are breeding grounds for numerous human rights violations. In institutions, people cannot even make basic decisions (what they do during the day, what and when to eat); not to mention bigger decisions (having a family or where they would want to live). Even if they are allowed to work, they often do so within the closed world of the institution, not in the open labour market.

People with disabilities have the right to be able to live independently, as part of the community, by receiving individualised support. Institutions deny both independence and inclusion. Under international law, governments including Hungary have an obligation to stop funding institutions and instead ensure that all people with disabilities can access the support they need to be fully included in the community. The process of moving people out of institutions and back into the community with support is called "deinstitutionalisation".

More information: http://ataszjelenti.blog.hu/2017/05/05/olyan_nincs_hogy_jo_intezet.

2. The European Union has allocated significant financial resources to replace the large institutions with new, smaller-scale, group homes. The first result of this is that by the beginning of 2016, more than 600 people left 6 large institutions. By the beginning of 2019, another 2500 people with disabilities are planned to be moved. Why are non-governmental organisations (NGOs) protesting now?

The projects, which cost nearly 24 billion HUF provided by the EU, do not comply with domestic and international law and regulations. Implementation of the projects in their present form will result in further segregation of people with disabilities and the continuation of an institutional culture. The group homes replacing the institutions are planned to be built far away from cities, in settlements with a few hundred inhabitants, in places which are inaccessible and lack adequate services. In addition, many group homes would not only be built in rural areas, but also on poor-quality land: flood plains, former industrial plantations, swampy-reedy areas or even adjacent to a sewage disposal plant. In many cases, the planned developments would take place within the existing and already segregated area of the large institutions. Every morning, minibuses will transport the residents of the newly built group homes to so-called 'Service Centres', which, in many cases will be at the former large institutions. The caring and feeding of people with disabilities would be the same as before, taking place in the institution. The group homes will function as mini-institutions. Residents will not be able to decide where they live, who they live with, will not be able to choose their carers, or make choices about their daily schedule. Thus, the EU project aimed at eradicating institutions will ultimately result in the creation of 189 new, albeit smaller, institutions. The institutional culture, the exclusion from society, the invisibility would remain and this would be a wasted opportunity for change.

3. What do the NGOs demand from the government?

The Validity Foundation, the European Network on Independent Living and the Hungarian Civil Liberties Union ask the government and the European Commission to suspend the current projects and to redesign the process. New projects should comply with the standards of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by Hungary in 2007 and directly involve people with disabilities in the planning, implementation and monitoring processes. Only this way can a successful process of deinstitutionalisation be achieved, following which people with disabilities can receive support that responds to their individual needs, that allows them to live independently, as part of the community; to finally live among all of us.

4. Who are these organisations?

Validity Foundation (formerly the Mental Disability Advocacy Centre): Validity is a dynamic community of professionals and volunteers, brought together by a desire to reverse injustice and segregation. We are experts in using the law in innovative ways – through strategic litigation and advocacy – to advance the rights of people with mental health issues and intellectual disabilities. Our staff are based in Budapest, Hungary and we work closely with an international network of lawyers, volunteers, organisations of persons with disabilities and human rights activists. For more information, please visit: www.validity.ngo

The European Network on Independent Living (ENIL): ENIL is a user-led, cross-disability rights civil society organisation, with members in 47 countries across Europe. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination. For more information, please visit: www.enil.eu.

Hungarian Civil Liberties Union (HCLU): a human rights civil organization, which has been dealing with disability-related issues since its establishment in 1994. From the spring of 2017 onwards, the HCLU Equality Project was created, which works against the state discrimination of the most disadvantaged groups in society and works for the creation of equal opportunities. The project focuses on the protection of Roma people living in extreme poverty and the rights of people with disabilities. For more information, please visit: www.tasz.hu.

5. Why are NGOs requesting the suspension of tenders?

The projects funded under the EFOP-2.2.2-17 scheme concern the closure of 29 large institutions, but the newly built group homes and services do not comply with EU regulations related to social inclusion, antidiscrimination laws, the Common European Guidelines, or the UN Convention on the Rights of Persons with Disabilities (CRPD), nor current Hungarian legislation. In their current form, 189 new mini-institutions would be created: group homes will be set up in remote, hard-to-access, sparsely populated, few hundred-person settlements, and residents will be driven by minibuses to the Service Centres, which will remain in the areas of the large institutions. People will spend their daily lives in these Service Centres, and will eat and work in them. No individualised support will be provided, and people with disabilities won't be able to decide on everyday or major issues affecting their lives. They will remain excluded from the community. Moreover, institutional culture will remain intact and, in fact, with the misuse of the 24 billion HUF, this will remain the case for decades. There won't be community-based services to help people with disabilities live with their families, and to prevent institutionalisation, and there will be no support, such as personal assistance, for people with disabilities to live independently.

6. What could be the consequence of suspending the Commission's subsidy? What about people with disabilities living in the institutions?

We ask the Hungarian Government to suspend current projects and totally redesign the scheme. We also turn to the European Commission to intervene to ensure that EU money is used in line with human rights standards, most importantly the right to live independently in the community. We are not asking for deinstitutionalisation to be stopped in Hungary: we consider it important to move forward with deinstitutionalisation, but in such way that would enable the thousands of people with disabilities still living in large institutions to live included in the community. The projects in their current form would only result in another form of exclusion and segregation. Missing this huge opportunity will not bring the required systemic change - the social inclusion and equal participation in society –, which is the goal of the EU funding. In light of Hungary's ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2007 (Act XCII of 2007), we call for the deinstitutionalisation process to be redesigned with the involvement of people with disabilities, their groups and organizations representing them. Suspension of the current scheme is needed to ensure that human rights are guaranteed before construction starts.

7. What do people with disabilities want? Who represents them?

It is difficult to answer this question precisely because of the minimal involvement of people with disabilities and their groups in the planning, implementation and monitoring processes so far. In reality, people with disabilities were not really asked.

It is certain that people with disabilities do not - like everyone else - want to live near desolate goat farms, adjacent to sewage plants, in flood-prone areas, in places where there are no shops, cafes or cinemas. In Hungary, members of disability organisations also strongly criticised the deinstitutionalisation process. In addition, the group of advocates of the only disability community in Hungary, 'Living Independently in a Community', is convinced that these projects should not be implemented in the present form. They have also conducted an action research on what people with disabilities need to be able to live independently, as part of the community.

8. Parallels with other EU projects

Regrettably, the Hungarian press has been loud in recent years about the waste of EU funding. Building housing in a flood plain or next to a sewage plant, and then every morning bringing people with disabilities by minibuses to 'Service Centres' established in the old institutions: this construction has about as much to do with community inclusion and independent living as the 39 million HUF EU funding which was used to build a 40-cm lookout at Bodrogkeresztúr. However, while the latter is a grotesque act of an expensive and bad joke, the inadequate support for people with disabilities takes life opportunities away from thousands of people with disabilities and thus seriously violates their fundamental human rights.

9. Cases where the European Commission successfully intervened in deinstitutionalization

Thanks to organisations advocating for the rights of people with disabilities, children and other groups at EU level, the European Commission has suspended funding in several cases where it was aimed at building or renovating large institutions - for example, in Slovakia and Bulgaria. More recently, the European Commission has intervened in the Czech Republic, where the government planned to build group homes housing 30 people each – in this case, new calls of proposals were launched.