



***Deinstitutionalisation in the work
of the Council of Europe Commissioner for Human Rights***

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**PACE Committee on Equality and Non-Discrimination
Joint hearing with the Committee of experts on the rights of persons with disabilities
“One of us? The right of persons with disabilities to live in the community”**

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I pay special attention to the rights of persons with disabilities in my work, and have concentrated on this issue in many of my visits. One of the reasons for that is the very obvious gap between the agreed legal standards, in particular those of the UN Convention on the Rights of Persons with Disabilities (CRPD), and the reality on the ground.

One of the key rights that the CRPD enshrines is the right of persons with disabilities to autonomy and to live in the community: this question is now framed as a human rights issue in international law, not one of social rehabilitation or welfare policy. The most obvious and direct violation of this right is arguably the segregation of persons with disabilities in large institutions; yet, here in Europe we are unfortunately still very far from eradicating such institutions.

The human rights violations these institutions engender are well documented, including in the case-law of the European Court of Human Rights and the reports of the Council of Europe anti-torture Committee (CPT). Yet, there are still European countries refurbishing existing institutions or even building new ones – sometimes even with EU structural funds. For example, in a recent visit to Romania, I was dismayed to learn that the number of institutions there have increased from 141 in 2005 to 335 in 2013, Romania investing 27.6 million euros in European funds into building and refurbishing such institutions. Those funds should have been used for community-based alternatives and supports for people with disabilities.

The problem is not only the suffering and inhuman and degrading treatment that persons with disabilities are often subjected to in these institutions, far from the public eye. These are also places where people suffer simply by virtue of having been deprived of any control over their life choices, regardless of the relative comfort of their living arrangements in some cases.

I have witnessed first-hand the toxic effects of institutions on their inmates: how they cultivate a feeling of helplessness; how the institution erodes one's confidence in one's ability to make choices; how it deprives people of life experiences and skills needed to build up autonomy and identity.

Many who could otherwise function in the community without a great deal of support have become unable or afraid to leave these institutions, because they have known nothing else. Even the director of a large institution in Hungary I visited recently agreed with me that many people in her institution should not have been placed there in the first place.

This explains why deinstitutionalisation is so high on my agenda, as it was for my predecessor. The issue paper of my office on this question includes, among other things, very clear recommendations to member states on how to proceed. I call on them to immediately stop new placements in institutions, while at the same time adopting clear action plans for phasing out institutions and replacing them with community based services in the medium term. Moratoria on new placements are crucial: even a temporary placement is likely to cause irreparable harm and constitute a clear violation of human rights.

While I cannot emphasise enough that deinstitutionalisation is a human rights issue, I do not wish to minimise the social and health benefits of deinstitutionalisation: study after scientific study demonstrates that results obtained in the community are far better for persons with disabilities and people around them, for comparable or even lesser resources spent.

We should also be aware that advances in deinstitutionalisation must be sustained. Even in countries where there has been some progress towards deinstitutionalisation, I observed important setbacks to achieving full inclusion. For example, the implementation of the recent law on autonomy in Spain and access to general services for persons with disabilities has been severely hampered by austerity measures. Even in a wealthy country such as Denmark, which abolished institutions in 1998, many municipalities have in recent years built large blocks of up to 80 apartments away from city centres, accommodating exclusively persons with disabilities. The material conditions in these facilities may be of a high standard, but I am convinced that clustering persons with disabilities together in such settings goes against the core of the right to live in the community and is like creating institutions under a different name.

We need to think beyond a narrow definition of “institutions” if we want to make the right to live in the community a reality. People, while physically in the community, can have their life choices severely restricted, because they have no access to the supports they require. Sometimes the supports are structured to suit the service providers and not the end users, and therefore subject to conditions that severely restrict interaction with the community.

This is why my Office’s issue paper, prepared with the input of disability NGOs, tries to identify what characterises progress towards genuine inclusion: the continuation of an “institutional” culture – only in smaller settings -- is not a sign of progress. Control over one’s life is the defining characteristic. In this respect, it is difficult to separate deinstitutionalisation from another very problematic area: the legal capacity of persons with intellectual and psychosocial disabilities. The legal and institutional frameworks on legal capacity and involuntary placements often feed an institution-based culture. I have witnessed very questionable practices in all the countries where I looked at this more closely. The case-law of the Strasbourg Court is now full of examples where national procedures have gone wrong (with safeguards failing to provide protection), because at the end of the day the judge, who is given the power to strip persons of their ability to make decisions, is more likely to listen to the psychiatrist than the person herself or himself.

In conclusion, I will continue to monitor very closely deinstitutionalisation and the implementation of the right to live in the community. Part of the problem is that policy makers in our member states are sometimes not even fully aware of the extent of their states’ human rights obligations when it comes to persons with disabilities. My monitoring therefore has to include a considerable awareness-raising dimension, and I hope to continue providing guidance through my country reports and general recommendations on these issues.