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Pitfalls in the implementation of the human rights of persons with disabilities

Keynote speech by Nils Muižnieks
Council of Europe Commissioner for Human Rights

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I am very happy to participate in this high-level meeting and thank the Latvian Ministry of Welfare and the European Commission for organising it. It is indeed crucial to take stock of the state of implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), and I have some perspective on the issue thanks to my monitoring work throughout Europe.

An important part of my job as Council of Europe Commissioner for Human Rights is to visit the 47 member states of the Council of Europe and publish reports on selected human rights issues, usually not more than two or three, that I consider of particular relevance to that country. Human rights of persons with disabilities have been one of the issues that I have taken up the most consistently. My main focuses in this monitoring work have been the right to live in the community and deinstitutionalisation, the right to legal capacity, and the right to an inclusive education. I saw the same issues, sometimes under different guises, come up in countries that are at first sight very different from one another, in Western and Eastern Europe, in EU and non-EU countries, and in countries of very different levels of economic development. Why is that? The short answer is that everyone is lagging behind international standards.

It has almost become a commonplace to talk of the paradigm shift from the medical model to the social model of disability. It is true that this shift is what states have endorsed when they ratified the CRPD which, with its human rights approach to disability, is nothing short of revolutionary.

Yet, based on my monitoring experience, my impression is the following: neither the member states nor the EU, which has signed up to the CRPD, have yet internalised that shift. They have been, on the whole, trying to tweak social care systems that are fundamentally non-compliant with the CRPD, rather than rethinking them from the ground up. In some countries where there were genuine attempts to reform disability policy, for example through legislative changes, these were not backed up by adequate resources. Very often, reforms were carried out haphazardly, outside a coherent action plan. And perhaps more importantly, the rallying cry of "Nothing about us without us!" which is the guiding spirit behind the CRPD was not sufficiently respected by policy-makers who still think that they know better.

I do not deny that many countries achieved important progress. My point is that, in comparison to the very long road ahead, this progress has been limited and frustratingly slow. What is more, many traps and pitfalls have become apparent along the way: what appears as progress at first sight sometimes turns out to be more of the same old approach, only repackaged.

Let me illustrate this point by looking at the right to education. The CRPD unambiguously sets out the obligation of including children with disabilities in mainstream education. I have looked at this issue in five EU countries so far (Czech Republic, France, Netherlands, Romania and Spain): I have seen a mixed picture, from segregation being the norm (Czech Republic) to the inclusion of the majority of children in Spain. I have seen some shocking statistics in the process, for example that almost 80% of children with autism in France do not have access to mainstream education, a situation for which France was repeatedly found in violation of the European Social Charter.

The life-long exclusion of people with disabilities starts with segregation in “special” schools or “special” classes. However, many countries still have not made the shift towards accepting inclusion as an enforceable obligation for mainstream schools. Instead of doing that, some countries appear willing to settle for some form of segregation, while using nicer-sounding concepts such as “appropriate education” (Netherlands) or even by labelling special schools “inclusive education centres” (Romania). Even access to mainstream schools is no guarantee of inclusion: far too often, children with disabilities, while under the same roof, are still separated from their peers in practice, educated only part-time, shut off from extended day programmes, or have much higher dropout rates. Usually this is due to the lack of resources to ensure accessibility or provide individual supports. Lack of resources can and should never serve as an excuse for sub-standard education for children with disabilities. Unfortunately, however, even existing supports have sometimes been withdrawn with austerity measures, for example in Spain.

Sub-standard education is one of the contributing factors to poor access to the labour market for persons with disabilities. Unemployment rates for persons with disabilities are still unacceptably high compared to the general population all over Europe. Practices such as sheltered employment are highly problematic, not only because they perpetuate segregation, but also because persons working there often do not benefit from ordinary labour law, for example with respect to the right to fair remuneration and trade union rights. Companies often disregard their obligations regarding reasonable accommodation and, where they exist, employment quotas for persons with disabilities.

There are many parallels between the failure to achieve inclusion in education and the labour market, and another area of concern to me, which is autonomy and inclusion in the community. Unfortunately, we are still far from eradicating the symbols of the most severe violation of this right: institutions. Apart from their tendency to lead to severe violations of human rights, including outright torture, institutions also invariably lead to a situation in which the convenience of service providers trumps the needs of persons with disabilities. They restrict contacts with the outside and limit life chances and the acquisition of skills necessary for autonomy. In a word, they take away one’s control over one’s life. They also hide persons with disabilities from the public eye, which as a result sees and stigmatises them as a homogenous group, a fertile breeding ground for prejudice. Whichever way you look at it, institutions represent a blatant violation of not only Article 19 of the CRPD, but of general human rights principles. Yet such institutions continue to blight our continent. There are still European countries refurbishing existing institutions or even building new ones. Until recently, some countries have done so using EU funds.

But even in countries where there has been some progress towards deinstitutionalisation, I observed major setbacks in achieving full inclusion. For example, in Denmark, which abolished institutions in 1998, many municipalities have built large blocks of flats away from city centres, accommodating exclusively persons with disabilities. Austerity led to restrictions in community-based services in Spain. Another major trap I have encountered, for example in Hungary, is so-called “deinstitutionalisation” into large group homes or “living centres”, which for all intents and purposes function like the old institutions. It is not the physical location of these structures that is the fundamental problem, it is the value base that guides them. As long as the wishes and choices of the person are not at the heart of these services, they can simply not be called community-based.

Control over one’s life is of course at the core of the CRPD. Yet this control continues to be fundamentally denied to a large segment of the population who are deprived of their legal capacity on the basis of an intellectual or psychosocial disability. Substituted decision-making, including full guardianship regimes where persons are literally stripped of their personhood in the eyes of the law and the society, are still very much the norm in the countries I have visited. I welcome the fact that Latvia, along with the Czech Republic, was among the first countries to abolish plenary guardianship, but one cannot stop there: the ultimate aim is to phase out all substituted decision-making and replace it with supported decision-making, as clearly stated by the CRPD. This is perhaps the topic where lack of progress is mostly the result of mental blocks, including from policy makers, legal professionals, and some psychiatrists. I believe that some promising pilot projects, including one here in Latvia, will play an important role in breaking down some of these barriers, but they need to be supported and scaled up, including by fundamental changes to civil codes.

This brings me to the role of the EU. Disability is one area where the EU has very clear competences as well as obligations under the CRPD – it must act accordingly. It is good that the EU has taken steps to avoid past mistakes, in particular by creating safeguards against the misuse of European Structural Funds. But it needs to do more now to make up for lost time: it must develop a coherent policy in all its areas of action, allowing for the full use of its many tools and programmes to improve respect for the rights of persons with disabilities. Very importantly, it must guide member states who are struggling in understanding, let alone implementing, some of their obligations. For instance, European Funds will be an essential component for implementing deinstitutionalisation plans in many EU member states. But in many countries I have heard from disability organisations that they were concerned about the design and implementation processes, expressing their fear of being shut out, apart from some token consultations. It is very important to prevent that from happening.

Effective enjoyment of the human rights of persons with disabilities requires that societies and policy-makers come to terms with extreme prejudice. This prejudice is fuelled by stigmatisation, exclusion and ignorance; tainted by paternalism and condescension. Our societies still think that some people are better off in institutions, that some people are simply too impaired to make any choice concerning their own life or to benefit from a decent education along with their peers. In other words, that agreed international standards are simply too unreasonable. It is this attitude which is still the main obstacle to the necessary transformation.

So the core of my message when it comes to human rights of persons with disabilities is this: first we must have the courage to listen and confront our own prejudices – they run very deep indeed. If you are a policy-maker, convince yourself first why things need to change, than work on changing them while taking the time to explain to the public why this change is necessary. The guiding question must always be: “Am I thinking of persons with disabilities as my partners in this process, or anonymous beneficiaries who should feel grateful for it?” That is the best protection against the many pitfalls.