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Monitoring the Human Rights of Persons with Disabilities in Europe

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

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The rights of persons with disabilities rank very high on my agenda. Since the beginning of my mandate, I have had 16 full country visits followed by reports. In six of these visits, I have decided to concentrate on the human rights of persons with disabilities (Austria, Czech Republic, Denmark, Estonia, Finland, Spain). Last week I was in Romania, where disability was also on my agenda.

My monitoring experience so far showed beyond the shadow of a doubt that there is a huge implementation gap between the legal standards, in particular those of the UN Convention on the Rights of Persons with Disabilities (CRPD), and the reality on the ground. This is not only a problem of lack of resources: I believe that in many cases, policy makers are not even fully aware of the extent of their states' obligations under the CRPD. This means that, for the rights of persons with disabilities, monitoring still includes a considerable awareness-raising dimension.

A good case in point is the right of persons with disabilities to autonomy and to live in the community. Unfortunately, Europe still has a long way to go even to eradicate the most obvious violations of this right; that is, the segregation of persons with disabilities in large institutions. The human rights violations such 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 they continue to blight the European landscape. There are still European countries refurbishing existing institutions or even building new ones – sometimes, shamefully, with EU structural funds.

The problem is not only the unimaginable suffering, inhuman and degrading treatment persons with disabilities are often subjected to in these institutions, far from any public scrutiny. These are also places where people suffer the indignity of having absolutely no control over their life choices. As the Supreme Court of the UK put it very eloquently in a judgment it delivered on 19 March, the “fact that my living arrangements are comfortable, and indeed make my life as enjoyable as it could possibly be, should make no difference. A gilded cage is still a cage”.

But even in countries where there has been some progress towards deinstitutionalisation, I observed major 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 relatively wealthy country such as Denmark, which abolished institutions in 1998, many municipalities have built large blocks of up to 80 or even more 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 runs against the full inclusion and control over one's living arrangements required by the CRPD.

Control over one's life is of course intimately linked to another very problematic area: the legal capacity of persons with intellectual and psychosocial disabilities. 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. There is some forward momentum, for example in Spain, Finland and also here in Austria, where I was

informed of the launching of a pilot project on supported decision-making. However, I am not convinced that member states are fully aware of the extent of their obligations under Article 12 of the CRPD, which clearly states that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. How else could one explain the fact that the right to vote of persons with intellectual and psychosocial disabilities are routinely taken away in many member States, along with their legal capacity, in blatant disregard not only of the CRPD but of the 2011 Recommendation of the Committee of Ministers of the Council of Europe on the participation of persons with disabilities in political and public life?

A very sensitive and problematic issue, affecting both the rights to legal capacity and to community living, is involuntary placements, and more generally coercion in psychiatry. I have spotted questionable practices in all the countries I mentioned, which have their roots in outdated legal frameworks, but also assumptions the validity of which are being increasingly challenged. The premise so far has been that involuntary placement of persons with mental health problems was an inevitable necessity, since they present a danger to themselves and others. The focus was very much on designing safeguards and controls, often judicial in nature. Well, very often these safeguards do not work. The case-law of the Strasbourg Court is now full of examples where national procedures have gone terribly wrong, where the person whose life is at stake has entirely lost his say in a process which has essentially been reduced to a dialogue between the judge and the psychiatrist.

We need to shift the focus to how coercion can be avoided in the first place, and how the person can best be supported in making healthcare choices. There are many good practices which show that alternatives may exist, such as the success of personal ombudspersons in Sweden, or psychiatric programmes such as the Open Dialogue approach to acute psychosis developed in Finland, which involves the patient in all treatment decisions and appears to have a very high success rate.

Education for persons with disabilities is another very problematic area where Europe is still far from realising the goal, so eloquently expressed in the CRPD, of ensuring an inclusive education system directed to “the full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity”. We celebrated the international day of autism last week. In 2003, The European Committee of Social Rights found in a collective complaint that France had violated its obligations under the European Social Charter, by failing to provide inclusive education to persons with autism. More than 10 years later, survey results published last week by the NGO “le collectif autisme” suggest that the overwhelming majority of persons with autism (78%) still have no access to education adapted to their needs.

In my own monitoring work, I looked specifically at the inclusion of children with disabilities in the Czech Republic, “the former Yugoslav Republic of Macedonia” and Spain, and saw a wide variety of situations, ranging from segregation being the norm (Czech Republic) to 78% inclusion in Spain, but with much higher dropout rates for children with disabilities. A very worrying development I observed in Spain was the effect of austerity measures on inclusive education: I learned that cuts to national and regional education budgets unfortunately led to children with disabilities being grouped in separate classes, or their individualised support being withdrawn in mainstream classes. Of course, this seriously compromises their prospects of receiving quality education.

More generally, I would like to raise the effects of economic crisis and fiscal austerity on the rights of persons with disabilities as a major preoccupation. Several countries announced postponements to their accessibility and inclusion goals. In many, disability benefits were among the first cuts to be made.

Some member states seem to forget that the additional support required by persons with disabilities is a means to neutralise the barriers they face, the barriers that stop them from contributing to society on an equal footing with everyone else. These supports are not optional, they are not just “another burden on society’s resources” or charity towards persons with disabilities. By removing the necessary supports, these states may be in violation of the person’s right to non-discrimination. The fact that many governments felt entitled to reduce these supports in the framework of budgetary cuts unfortunately makes me think that our societies have not yet left behind the charity approach in favour of a rights-based approach. Speaking of discrimination, I also witnessed how anti-discrimination and equal treatment frameworks, where they exist, are often incomplete when it comes to disability. Just

to give an example, the duty to provide reasonable accommodation, for employers or schools for instance, is more often than not very well defined and employers and authorities are not even aware of their obligations

Finally, a very worrying development concerns reports of increasing hate speech and hate crime against persons with disabilities, which were exacerbated by toxic debates about disability benefits in certain countries. Disability-based hate crime is arguably among the least visible forms of hate crime, despite the fact that research by the EU Fundamental Rights Agency indicates that violence and harassment are among the principal barriers to inclusion of persons with disabilities. .

All this brings me to the main point I would like to make: I believe that effective monitoring of the implementation of international standards on rights of persons with disabilities, and in particular of the CRPD, will be crucial if we do not want to compromise the significant achievement the international community obtained by agreeing on very progressive standards. We need to make sure that states are held accountable to those standards, and do not settle for anything less. This is all the more important when the rights in question are complex and wide-reaching, such as the right to live in the community. This is why, for example, the issue paper of my Office on this right contains suggested indicators and guiding questions to help with monitoring.

The CRPD provides for a monitoring system through the Committee on the Rights of Persons with Disabilities. However, it is no secret that the resources at the disposal of this system are very scarce compared to the magnitude of the task. As far as our continent is concerned, I think that the Council of Europe has much to contribute. In fact, it has already contributed a great deal: the monitoring work of the CPT and of the European Committee of Social Rights, as well as the case law of the European Court of Human Rights and again of the Committee of Social Rights through its collective complaints mechanism, have been instrumental in advancing key rights. The Council of Europe has further produced important texts for policy makers, through its intergovernmental work, in particular the Disability Action Plan, as well as key recommendations of the Parliamentary Assembly.

But we need to do more. Most importantly, I think that the voice of persons with disabilities and their representative organisations need to be heard more loudly and more often before Council of Europe bodies. This is precisely the reason for which I decided to make my first third-party intervention to date before the European Court of Human Rights in the case of *The Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania*. I have thus argued in favour of easing standing requirements for disability-rights NGOs before the Court, when not doing so would effectively result in persons with disabilities having no reasonable prospects of seeking justice for violations of their Convention rights.

If the CRPD is such an important achievement, the lion's share of the credit goes to the contribution of persons with disabilities to the process. Monitoring must follow suit. The Convention is very clear: states have to put in place independent monitoring mechanisms and "civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process".

Unfortunately, like in all areas of life, persons with disabilities also face huge barriers to their direct involvement in the work of national and international monitoring mechanisms, as well as in designing policies. I think that this issue needs specific and urgent attention. Persons with disabilities make the most convincing case for their rights and their needs, provided that they are supported adequately and others listen. But we cannot listen unless each one of us faces up to her or his prejudices. These prejudices are not always easy to detect, because they are often very deeply ingrained, wrapped in layers of pity or well-meaning condescension. We, governments, parliaments, international organisations, need to abandon the arrogance of thinking that we know better than "them". Persons with disabilities do not need paternalism or charity: like everyone else, they are full holders of rights; and, like everyone else, they are entitled to the attention, empathy and humility one owes to a fellow human being whose human rights have been violated.