



Human rights: a reality for all
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Check against delivery

I am very happy to be back in Cyprus to participate in this Conference launching the Council of Europe Disability Strategy 2017-2023. One of the issues I dealt with during my last visit here, in 2015, was the impact of the economic crisis on vulnerable social groups. The negative effects of the crisis and the ensuing austerity measures on a wide range of human rights, including the right to health, have been broadly demonstrated. My country work clearly indicates – most recently in Greece, but also in Estonia or Spain – that persons with disabilities are particularly affected. In many countries, disability benefits were among the first cuts to be made, while accessibility and inclusion goals were postponed. However, the additional support required by persons with disabilities is not optional. It is necessary to neutralise the barriers that prevent these persons from contributing to society on an equal footing with everyone else. As such, by removing this support, states may be in violation of the person's right to non-discrimination. While the economic crisis has made the situation considerably worse for them, persons with disabilities face obstacles to the full enjoyment of their human rights also in countries which did not have to undergo extensive austerity measures. This is what I found on the occasion of many of my country visits, including to Austria, Denmark, Finland, France, Norway or Belgium.

In this context, the new Council of Europe Disability Strategy was awaited with great interest. It is today warmly welcome.

This strategy is a comprehensive document, encompassing all civil, political, economic, social and cultural rights safeguarded by the ECHR, the European Social Charter and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Let me express appreciation about the emphasis put on the CRPD, which marks a 'paradigm shift' from the medical model to the social model of disability. It should therefore be both a starting point and a benchmark for implementing any effective disability policy. I use this opportunity to urge Council of Europe member states which have not yet signed and ratified the CRPD and its additional protocol to do so at the earliest opportunity. This is of paramount importance to improve the protection of the rights of persons with disabilities.

Good standards are necessary, but not sufficient. Since the beginning of my mandate, I have witnessed on many occasions a huge implementation gap between the legal standards and the reality on the ground. This new Council of Europe Disability Strategy gives guidance to member states on how to fill this gap. It also defines priority areas, some them being particularly close to my heart.

First of all: the promotion of equality and non-discrimination, in particular through inclusive education. The CRPD sets out the obligation to include children with disabilities in mainstream education. I have looked at this issue in a number of European countries and seen a mixed picture: from separate education 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. In Belgium, a high number of children with disabilities are educated in specialised schools, separately from other children, with little prospect of being reintegrated into mainstream education. Other countries appear to settle for some form of segregation, while using nicer-

sounding concepts such as “appropriate education” (Netherlands) or even labelling special schools as “inclusive education centres” (Romania). However, 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.

We need to remember that the life-long exclusion of people with disabilities starts with segregation in “special” schools or “special” classes. These special arrangements are generally characterised by lower expectations, often entail lower quality of teaching, and sometimes mean worse material conditions and restricted availability of activities. In all cases, they reinforce and legitimise the marginalisation of children with disabilities’ in later stages of their lives. We should also keep in mind that segregated education is not only harmful for children with disabilities. It is also detrimental to their peers, teachers, and the whole community who is deprived of knowledge about human diversity and essential life skills.

The second priority area is the equal recognition before the law, which refers to legal capacity. As the Council of Europe Disability Strategy stresses, control over one’s life is a fundamental requirement for the full enjoyment of all human rights. However, this control continues to be 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 (whereby 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. Some countries, including Latvia and the Czech Republic have abolished plenary guardianship. This is a major step forward, but we cannot stop there. The ultimate aim is to phase out all substituted decision-making and replace it with supported decision-making, as clearly required 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. There are good practices and promising pilot projects in Europe, which the Strategy will contribute to identify and disseminate. They play an important role in breaking down some of these barriers, but they need to be supported and scaled up, including through fundamental changes to civil codes.

I cannot refer to the right to legal capacity without mentioning the issue of involuntary placements, and more generally coercion in psychiatry. In many European countries, out-dated legal frameworks and assumptions, the validity of which is increasingly challenged, result in highly questionable practices. 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. However, very often these safeguards do not work in practice. 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. This is why I expressed a negative opinion on the idea, currently being pursued in the Council of Europe, of drawing up a legal instrument (in the form of an Additional Protocol to the Oviedo Convention) aimed at reviewing legal safeguards concerning involuntary placement and treatment of “persons with mental disorder”.

What we need to do, instead, is 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. Medical treatment based on free and fully informed consent should be prioritised, with the exception of life-threatening situations, when there is no disagreement about the absence of decision-making capacity of the person. There are many good practices which show that alternatives to coercion 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. The signature and ratification of the Optional Protocol to the UN Convention Against Torture and the establishment of adequately resourced National Preventive Mechanism to strengthen institutional safeguards against ill-treatment are also essential steps which should be taken by all Council of Europe member states.

The last priority area on which I would like to focus relates to freedom from exploitation, violence and abuse. As the Strategy rightly stresses, “living arrangements in isolation or segregation from the

community as such are not only contrary to the right to live in the community as enshrined under [CRPD], but also often give rise to some of the most serious human violations in Europe.” I fully agree with this observation. The human rights violations large 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. The problem is not only the 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.

I also fully agree with the conclusion which the Strategy draws from this observation: “the widely-documented violence and abuse in such arrangements is one of the many reasons for the need to progressively replace them with community-based services.” This aim cannot only be achieved by the abolition and closure of large institutions. It also requires moving resources from institutions to the development of individualised support services and addressing the whole institutional culture, by placing the wishes and choices of the individual at the heart of the provision of services. The creation of new living settings should be compliant with CRPD and not lead to opening new - even if smaller - institutions, a trend which I unfortunately had to highlight in the context of some of my country work. The more specific services are provided within the residence, the less opportunities for contacts with the outside world are available to the residents in practice.

Building an inclusive society and making human rights a reality for all, as the title of this conference invites us to do, is not possible without the involvement of persons with disabilities and their representative organisations. The rallying cry of “nothing about us without us!” which is the guiding spirit behind the CRPD is not yet sufficiently respected by policy-makers. I welcome the fact that the Strategy endorses this principle and I hope that the voice of persons with disabilities will be heard more loudly and more often before Council of Europe bodies. The on-going discussions concerning the Draft Additional Protocol to the Oviedo Convention mentioned earlier is an opportunity to implement this principle which should not be missed.

Significant steps forward were made in recent years. Good standards were set, first and foremost the CRPD. Large funds are available, especially at EU level, which can be devoted to the implementation of disability policies. Excellent tools exist, that can be used in an innovative way to promote these policies. The Strategy stresses that the Council of Europe programmes should promote human rights-based and gender sensitive disability-related training. I believe that it is the case of the HELP programme which could, for example, contribute to ensure that judicial authorities review legal capacity cases in a more human rights compliant way.

We now need to be more ambitious to make further steps forward. This is what the protection of human rights of people with disabilities requires. This is what this strategy will help us doing. This is how we will succeed in creating really inclusive societies.