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Disability Rights: From Charity to Equality

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“Human Rights for persons with disabilities”

Keynote speech by Thomas Hammarberg
Council of Europe Commissioner for Human Rights

Thank you for inviting me to this very important meeting.

It is estimated that more than 10% of the world population lives with a disability. For Europe, this corresponds to 80 million Europeans. Some of these persons are born with a disability, many acquire it later through illness, accident, or violence. Statistics also show that in countries with life expectancies over 70 years, a person will spend 8 years on average living with disabilities. An interesting expression which is sometimes used in the disability rights community is “temporarily able-bodied”, a reminder to everyone that many of us will acquire a disability at some point in our lives.

For something as prevalent as disability, the attitudes of our societies have been remarkably backward and slow to change. Issues relating to disability tend to be completely ignored, marginalised, or subject to a condescending attitude of pity and relying on charity. For far too long, this attitude was reflected in policies focusing only on institutional care, medical rehabilitation and welfare benefits.

This traditional attitude is no longer acceptable. Although one should not underestimate the value of the noble sentiments behind charity, no amount of charity can solve the problems caused by the discrimination faced by persons with disabilities.

The last decades have been marked by a shift in thinking. From viewing disability as a personal problem that needs to be cured (the medical model), we have come to see the source of the problem: the society’s attitude towards persons with disabilities. This means that we have to act collectively as a society in order to remove the barriers that hinder persons with disabilities from living among us and contributing to our society, and to fight against their isolation in institutions or in the back-rooms of family homes. Finally, there has been a shift from welfare policies and charity as the only tools for dealing with disability, to an approach based on human rights and equality.

In short, persons with disabilities used to be considered as victims and *objects* of pity, charity, institutional care, medical rehabilitation or welfare benefits. This view has been replaced by one that regards them as active *subjects* with equal rights, capable of taking their own decisions and contributing to our societies.

Language has been a very important part of this shift in thinking. In fact, language used for dealing with disability issues can be a very powerful barrier to progress. In some European countries, for example, the official word used for a person with disability is an “invalid” – this immediately projects a very negative image onto the person and sends the wrong signal to society.

One of the key treaties of the Council of Europe, the European Social Charter, illustrates the shift in mentality and language very well. This treaty, which was first opened for signature in 1961, was substantially revised in 1996. It thus shows the way in which the mindset of its drafters had evolved in the intervening 35 years. Just compare the titles of the article dealing with disability: In 1961, this article was entitled “the right of physically or mentally disabled persons to vocational training, *rehabilitation* and *social resettlement*”. 35 years later, this became “the right of persons with disabilities to independence, social integration and participation in the life of the community”. Unlike the patronising approach of the 1961 version, the revised Social Charter obliges states to make sure that persons with disabilities are employed “in the ordinary working environment” or attend mainstream schools, by adjusting the conditions to their needs.

Such a radical shift in about 30 years is no mean feat. This can only be explained by the success of the disability rights movement itself, and their motto “nothing about us without us!”. Through their organisations and relentless advocacy, persons with disabilities have become actors in shaping policies that affect them, both at the national and international levels.

The most remarkable achievement of this movement is of course the UN Convention on the Rights of Persons with Disabilities, which entered into force in 2008. This Convention codifies the shift in thinking in a legally binding instrument. Non-discrimination, accessibility, inclusion in society and the freedom to make one’s own choices are core principles. Each article sets out one of the basic human rights of persons with disabilities, and what the states must do to transform that right into a reality.

For example, to guarantee political rights states must ensure that persons with disabilities have the opportunity to participate in the public debate, to vote and to be elected. States must make sure that voting procedures, polling stations and ballot papers are accessible and easy to understand. They must make the necessary changes to offices and provide equipment so that politicians with disabilities can hold public positions.

The Convention has been signed by 148 states and ratified by 100, and has now become the global benchmark. In Europe, it has been complemented by the Council of Europe Disability Action Plan 2006-2015 which contains many concrete measures to guide states in implementing their obligations under the Convention.

While this profound shift has occurred in the disability rights community, and shaped recent international standards and national policies in many countries, it is far from being accepted everywhere or internalised. In reality, persons with disabilities still face widespread discrimination in Europe and all over the world.

- For example, it is still a very common problem that children with disabilities are denied their family and educational rights because ordinary schools are not prepared or willing to meet their needs. So-called special schools are sometimes of lower quality, or they make integration into society more difficult by postponing it, thus perpetuating the problem.

- The treatment of mentally disabled persons remains simply shocking in several European countries, where they are kept locked up in institutions no better than bad prisons, with widespread ill-treatment and abuse. In general, persons with disabilities are prevented from making choices about their health, well-being and how and where they want to live. This is something that nobody would accept for themselves, why should it be acceptable for persons with disabilities?

- Job opportunities are still limited due to discriminatory practices and physical barriers at the workplace, in public transport or at home. Everywhere, unemployment among persons with disabilities is much higher than within the general population.

- People with disabilities are in some cases also denied their fundamental right to vote and others may not be given a genuine chance to cast a ballot because election procedures have not been made accessible.

Some of the most obvious human rights violations faced by persons with disabilities have been condemned by the European Court of Human Rights. An example is the policy in some European countries to strip persons with mental health problems or intellectual disabilities from their legal capacity or their right to vote, indiscriminately and automatically. Indeed, it is unfortunately still acceptable in many legal systems to treat persons with mental and intellectual disabilities as non-persons, whose decisions have no value whatsoever.

As these examples show, discrimination of persons with disabilities can take many forms. It can be very visible, such as segregated education and denial of employment opportunities, or even hate crimes directed against persons with disabilities.

But discrimination can also be very subtle, and operate through physical, psychological and social barriers resulting in social exclusion. Achieving meaningful equal rights for persons with disabilities will require those barriers to be brought down.

The principle of ‘reasonable accommodation’ is crucial for this. This concept is defined in the UN Convention as “modification and adjustments not imposing a disproportionate or undue burden” to ensure that persons with disabilities can enjoy their human rights on an equal basis with others. States, employers and societies as a whole have to internalise this principle. There should be clear regulations setting out their duties, with appropriate remedies and sanctions when these regulations are not respected.

But it is not enough to adapt existing conditions to the needs of persons with disabilities, these needs must also be taken into account when designing new products, services, buildings and infrastructure, for example when developing new software or a website. The Council of Europe issued some recommendations concerning this question in October 2009, entitled “achieving full participation through Universal Design”: for any product or building, accessibility for everyone should be a concern from the moment of conception.

Achieving equality and respect for the human rights of persons with disabilities is not a niche problem. On the contrary, for any meaningful result, these principles and this shift in thinking will have to be translated into all policy areas, or ‘mainstreamed’. This is why it is so important that disability issues are firmly embedded in all human rights discourse and action of all parties, including NGOs.

The previous comments on charity might have given the wrong impression that all charity is bad. It is true that it was easy to see charity as a barrier to progress in the years when the disability rights movement was beginning to assert itself. Indeed, the traditional charity approach tended to reinforce the idea that persons with disabilities were poor, helpless, unable to fend for themselves, and thus fundamentally unequal. Also, receiving charity could be seen as undermining self-esteem, creating shame and a feeling of dependency.

But with the general shift in thinking, charities themselves have been transformed to a great extent, and their actions increasingly incorporate these principles. For example, some charities (or NGOs, as the term ‘charity’ itself is being slowly replaced) advocate very successfully for the human rights of persons with disabilities; others provide facilities to persons with and without disabilities at the same time, fighting against segregation. There is also a tendency to reduce the use of pity and the “tragic but brave” image of disability for fundraising. Once more, this is largely thanks to the awareness-raising activities of disability rights groups. It is also encouraging that persons with disabilities themselves are increasing their say in the form the charitable action takes.

We should also challenge the idea that people with disabilities can only be beneficiaries of charity. An inspiring example is the ABILIS Foundation, which was founded by people with disabilities in Finland. This organisation supports projects initiated by persons with disabilities in developing countries that promote equal opportunities in society through human rights, independent living, and economic self-sufficiency.

Full removal of social, legal and physical barriers to the inclusion of persons with disabilities will take time and require resources. But it has to be done, because no society can afford to marginalise so many of its citizens.

Unfortunately, the recent economic crisis has led to the questioning of policies aimed at levelling the playing field for persons with disabilities. A very worrying trend in Europe is to see the resources allocated to this cause as a kind of charity of the state and society as a whole towards people with disabilities.

We have to fight this perception, if we want the progress of recent decades to continue, and not to fall into a very dangerous trap, again. In Europe more than anywhere else, we still have chilling memories from our recent past, of how such perceptions of persons with disabilities as a drain on society’s resources led to their persecution, or even systematic killing.

Persons with disabilities have the right to fully contribute to society as voters, politicians, employees, consumers, parents and taxpayers like everybody else. If resources are being used to make that right a reality, it is not because this is the kind or charitable thing to do, but because it is the *right* thing to do. Economic considerations must not prevail over human rights, and financial costs cannot be used by states to postpone indefinitely the realisation of the international standards that they agreed to.

We therefore have to work, out of a sense of responsibility for each other’s welfare, equality and human rights, and together with persons with disabilities themselves, in order to make sure that these rights become effective.

The US President Franklin D. Roosevelt is one of the best-known political figures with a disability. As he put it: "we know that equality of individual ability has never existed and never will, but we do insist that equality of opportunity still must be sought".