

STEPS conference Lidingö

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Mr. Lars Lööv, Swedish Disability Ombudsman:

Measures to promote the rights of persons with disability in the national perspective

I am truly glad of the opportunity of coming here and taking part in this conference, and I hope that what I have to say now will make a useful contribution.

First, let me briefly introduce myself. My interest in disability questions really started in August 1989" with the birth of my son, Carl Fredrik. Carl, Fredrik has Down's syndrome, which means that he has an intellectual disability. Almost exactly three years later I began working as a legal adviser with the Swedish association of persons with intellectual disability. In 1997, following a short spell in the Government Offices, I was elected Chairman of HSO - the Swedish Co-operative Body of Organizations of Disabled People. I resigned that position in May 1999, when I was appointed Disability Ombudsman.

What is the Office of the Disability Ombudsman" and what role does it play?

To answer these questions, I will have to fill you in a little on the situation in Sweden and the structures prevailing here. First, though, I should make clear that the Disability Ombudsman is a person but also a national authority - the Office of the Disability Ombudsman. The Ombudsman personally is appointed by the Government for a six year term, with the possibility of a three-year extension. The Office today is a small organization with a staff of 19, myself included. A majority of us are trained lawyers, but also architects and engineers.

In Sweden as in so many other parts of the world" there is a profound tradition of taking care of people with disabilities. In fact we can see a centuries-old tradition of caring for people who have not measured up to the normality requirements of the ruling classes. Usually this has been done in special institutions" most of them segregated from the rest of society.

In Sweden these institutions persisted until the end of the 20th century, and the last residues have in fact survived the change of millennium. The important thing, though, is that, even if the walls of the institutions have

been torn down, the tradition which prevailed in their day" is by no means dead and buried. People with disabilities are still looked on primarily as an object of care and concern, not as human beings with rights and obligations.

Parallel to, or rather as an important cause of, the developments that have taken place, Sweden has experienced a steep growth of prosperity. This has also been of benefit to people with disabilities. It means that Sweden today, by international standards" has relatively efficient systems of medical care, rehabilitation" support and service. Or" in the terms of the Standard Rules, good prospects of participation and equality.

Despite these good prospects, Sweden is a segregated country. This segregation can be, and during the past ten years has been" described in many different ways. The biggest review was undertaken by a parliamentary committee appointed by the then Minister of Health and Social Affairs" Bengt Undqvist, at the beginning of the 1990s, but I would like to describe it with a few examples from the surveys carried out by the Office of the Disability Ombudsman during the second half of the 90s.

- 56 % of Sweden's compulsory schools are not accessible to pupils, teachers or parents with mobile disabilities.
- 86 % of schools cannot offer an environment suitable for persons with allergies.
- In more than 20 % of Sweden's municipal council chambers, people with hearing impairment have no chance of hearing what is said.
- More than 25 % of Sweden's national and local authorities have no information in adapted form - Braille or easy to read Swedish, for example
- and are not producing any.

Another obvious example is the Swedish schooling system with a parallel but separated legal basis for children with a cretin diagnose" mental disability or learning disability if you prefer that. The right to support is then connected to the diagnose and not the individual needs for the child.

One could quote any number of examples of segregation in travel, at work., in education and the leisure sector. Why is this? Why is Sweden so inaccessible and segregated even though we for example have had legislation ever since the mid-1960s for the very purpose of making the built environment accessible? Why do we allow certain people to be excluded from the arenas which most of us take for granted and, above all, why is not everyone allowed to participate in the democratic processes which are the very core of our social edifice?

In reports to the Swedish Government I have tried to explain the possible reasons for this. First and foremost, in my opinion, it is due to our tradition of looking on people with disabilities as objects of care and concern. They are an indeterminate" faceless group which society is expected to look after without other people's everyday lives being affected. The second problem is that, because of our advanced welfare system, we think we are very good at looking after people with disabilities. This has led to a national arrogance, which blinds us to the serious shortcomings of our society.

The parliamentary committee I mentioned just now already described the same thing, in its own way, back in 1992" when it proposed a number of measures, in several sectors of society, which would strengthen people's position as citizens. Among other things the committee proposed both constitutional and other statutory safeguards against discrimination. And to monitor compliance with this new legislation it recommended setting up the Office of the Disability Ombudsman.

But Sweden was not ripe for regulations prohibiting discrimination on grounds of disability. Nothing came of the committee's proposals. There were several reasons for this, one of them being our worst economic recession in over 50 years. But I don't believe that was the main problem. The real trouble is a failure to understand that discrimination is something that happens in Sweden and that discrimination can have to do with disabilities. With no legislation, no Office of the Disability Ombudsman materialized either - not that time.

Instead, again as a result of the committee's recommendations, we had a reinforcement of supportive arrangements, services, care and rehabilitation. Instead of being strengthened as citizens, people with disabilities were strengthened as recipients of community support. Don't misunderstand me. That reform was right and proper in many ways. It did actually improve opportunities of participation and equality. Lately, though, I have often wondered whether what happened on that occasion also compounded the arrogance I have already mentioned and in this way obscured the need for measures of other kinds.

In December 1993 a unanimous General Assembly adopted the UN Standard Rules. I propose now to consider, not the rules themselves but, what they led to in Sweden. What happened was that the then Government, as a means of implementing the Standard Rules in Sweden, revived the notion of a Disability Ombudsman. It is perhaps not so very strange. Sweden has a long tradition of Ombudsman activities and there are today several Ombudsmen charged with monitoring different aspects of society.

In the spring of 1994 Sweden's parliament passed an Act empowering and requiring the Government to establish the Office of the Disability Ombudsman. The Ombudsman's overarching task, as defined by law, is to supervise the rights and interests of people with disabilities, with a view to their full participation and equality in the life of the community. In purely formal terms, then, the Disability Ombudsman is accountable to the Government, but the tasks and annual budget of the Office are mainly determined by the parliament.

The Disability Ombudsman's broad mandate means that questions of every kind anywhere in society can land on my table if they affect the rights and interests of people with disabilities. But different questions can of course be somewhat differently treated. After all, separating problems and responsibilities with reference to one characteristic of an individual person is not a very efficient way of doing things. Instead a heavy responsibility rests with the public authorities and others who are charged with supervising different systems. For example, the National Board of Health and Welfare, in its supervision of health services and medical care, and the National Board of Housing, Building and Planning

in its examination of building processes, have to bear in mind the needs of people with disabilities. In cases like these, the main task of the Disability Ombudsman is in various ways to try to ensure that the responsible authorities really do what is necessary. This perspective was strengthened two years ago when The Government pointed out a sectorial responsibility for 14 national authorities. In other sectors of society" no such express responsibility exists and the Disability Ombudsman must directly observe and examine developments more closely - for example" access to a restaurant or the design of information supplied by a public authority.

There is one field in which" since 1st May 1999, the Disability Ombudsman has had a specific task that has strengthened our statutory possibilities, namely the task of supervising compliance with the new legislation prohibiting discrimination at work on account of disability.

How do we address this task?

First of all, we deal with individual cases referred to us by people with disabilities. These cases can be divided into two types. Firstly, there are advisory cases in which the Disability Ombudsman tries" mainly through legal advice, to strengthen the position of individuals by advising them on the rules and on ways of obtaining their rights. Complaints are the other

type of case. If a complaint concerns discrimination at work and a person's trade union does not press the matter" the Disability Ombudsman has extensive powers of investigating the matter and, as a last resort, the possibility of suing an employer in the Labor Court. Since 1 March 2002 a similar protection for university students is in power. In complaints of other kinds the Disability Ombudsman has certain powers of investigation but no powers at all to compel anyone to comply with our findings. Instead these cases end with the Disability Ombudsman making an official statement in the matter.

The Disability Ombudsman is also charged in more general terms with following up and analyzing the living conditions of people with disabilities. We do this mainly by carrying out our own investigations. For example, we have investigated the accessibility of both national and local authorities. To take another example, we have investigated conditions in the labor market for people with disabilities. This latter aspect has been judged so important by the Government that the National Labor Market Board has now been instructed to carry out an investigation of this kind every two years. Another important way of observing developments is by looking at what other people do - "other people" being both organizations of the disabled and, not least, the research community.

Information and knowledge transfer make up the third pillar of the Disability Ombudsman's duties. It is our task in various ways to disseminate knowledge of the conditions in which people with disabilities are living. That information is based above all on knowledge we acquire through our own activities. I would also like to stress the importance of those activities. Remember that this is where the Standard Rules begin.

The office also hosts a national center for accessibility but that part of the office will probably be a part of a new national authority in a year or so.

The Standard Rules are at the center of everything the Disability Ombudsman does. As I said, they were the reason for establishing the Office in the first place, and, together with the Act establishing the Office of the Disability Ombudsman, constitute the foundation of everything we do. And then, if we turn to consider where the Standard Rules derive their substance, the preamble makes this perfectly clear. They refer to human rights as enshrined in all the important conventions adopted, mostly by the UN General Assembly, on the subject of civil, political, economic, social and cultural rights. Viewed against this background, the Standard Rules are an instrument for interpreting those other conventions, an extra

guarantee that when we say "all human beings" we mean just that. The commission for human rights in resolution 2000/51 confirmed this.

This makes an important difference to what we can learn from what I now have to say. Even with a wall-to-wall social welfare system, people with disabilities do not have full social participation and equality merely because they have a share in the support, which the community provides. Instead a system of this kind creates widespread dependence. In a report which he wrote in Sweden in 1999, Bengt Lindqvist has called this public charity. He goes on to say that "in a system based on people with disabilities mainly being recipients of support from the community, the support can actually be called into question. Things can even go so far that, in systems of this kind, almost without anyone batting an eyelid, debates can be waged for or against the most fundamental right of all, the right to life. Human rights are the way out of this predicament. Everyone must be looked on as a citizen with rights. In order for everyone to be included, everyone must be able to vote, to own property, to form a family, to work, to have equal access to medical care and to obtain social support.

For people with disabilities" this indivisibility of human rights is essential and obvious. Undeniably, some people need social or medical support in order, for example" to be able to exercise their civil right of voting in general elections. This indivisibility makes the UN Convention on the Rights of the Child extra important, as being the only convention with indivisibility built into it. The UNCRC is also important because it is, through our children that we can lay the foundations of change.

It is my firm conviction, then" that the road to full participation and equality goes by way of human rights. This is why human rights are the foundation of all that the Disability Ombudsman undertakes. In the transaction of business, in general follow-up work and in our information activities. This is not always an easy task, because in Sweden we are more accustomed to talking about how other countries, in our opinion', should address human rights than with contemplating our own position. But, partly as a result of consistent efforts by the Office of the Disability Ombudsman, we can now see the first signs of the necessary change of perspective in Sweden. The national plan of action (under Rule 13 of the Standard Rules) adopted on 31st May 2000 by the Swedish parliament contains several important observations. The plan states that disability policy is ultimately a question of democracy and that one of the concerns of disability policy for the future must be to combat discrimination. When this fundamental vision starts to impact on practical politics, a number of very important things will start to happen in Sweden.

Thank You for Your attention