Slovenia: Rights and Discrimination

***Elena Pečarič**, Ljubljana*

Recent events regarding the publication of the health status report of two Slovenian politicians (a member of European Parliament and President of the Republic of Slovenia) drove me to reflect on, describe and compare the two events with common practice, which pertains to disabled persons. The public is disgusted by the fact that health status of so important and influential individuals was made public by none other than a (retired) doctor. However, no one even flinches, let alone is disgusted by the fact that such things happen to people with the status of a disabled person. No one even thinks such doing is wrong, although personal information is disclosed to the public on a common basis. It is expected from disabled persons to get used to such maltreatment and stop complaining. Of course these people are not widely known to the public and their health and social status is useless to anyone but the people who make money by abusing the information they have about them. Therefore, no one seems to care that their files, documents and expert opinions regarding their health and social welfare are being passed among various institutions, disabled persons societies and experts. Consent of the individual is rarely requested or required as the affected persons are seldom notified about such matters. Disabled persons are usually unaware about the content of their files and are thus unable to challenge or express doubts about the correctness of expert reports and examination results. How could a layman even think of having doubts about expert's opinions? Mistakes, errors and abuses are often made, however an individual only rarely gets a chance to point them out. Expert opinions, judgements and decisions carry much more weight than an opinion of an individual who is, on top of that, disabled. Experts have the power of authority and the authority of power and are backed by institutions that are part of the system. The only means left is civil action (provided, of course, that the individual has the proper financial backing for such a feat), however, in our experience taking matters to the court borders to masochism. To add insult to injury, most lawyers won't take such cases because they don't believe they have any chance to win.

We must confess that conditions regarding court procedures in the field of social welfare have improved significantly in the last ten years, at least on a formal level. At least now people talk about the rights of the user, freedom of choice and co-decision, however in practice we are still experiencing the same setbacks as before.

As we do not wish for this essay to become nothing but whining and lament over our state, we have decided to list some of the discriminations based on the label "disabled person".

1. In 1996 I lodged a civil action against ZPIZ (Pension and Disability Insurance Institute of the Republic of Slovenia), more precisely against the Invalidity Commission, which was supposed to decide on my disability grade. I will not burden you with details, however, the suit is still ongoing. In the last ten years

there were only three court proceedings, and one of the doctors has already passed away. The conflicting sentence in the report is not only insulting to me. It defines me as mentally disabled and thus nullifies everything that I have been fighting and living for for the last decade and more. However it is even further-reaching as it represents an expert opinion of an important institution, which gives it an immense weight and lasting validity. It is an official document and a basis on which the decision on my disability grade is made, and a required document for enforcement of basic rights in several fields. What needs to be stressed is that this document had been drawn up behind my back and I had no knowledge of its existence until I stumbled upon it by accident. It seems that I was never supposed to have access to it. When I began reading it I felt ashamed and degraded but I thought that it was just another event in my life that I would soon forget, until I came to that sentence. I even had difficulties with persuading my own lawyer as to how broad and far-reaching effect it can have. To summarize: just like crime, mental disability must be generally backed by facts, however it seems to be attributed to every disabled person without any kind of examination. The Slovenian system of social and health care allows for and favours such actions, which means that an individual, who does not wish to be proclaimed unfit for work must prove that he or she is not “mentally disabled”. Only then is he allowed to lead a “normal” life.

2. The second case is the case of an individual with a severe physical handicap who lived at the Home for Older People (HOP) in Bežigrad, on a so-called younger disabled people ward. “You’re lucky,” they told him, saying that it was the best solution for disabled people who need non-stop care, and that certain advantages were unavailable elsewhere. As a certified evaluator, certified by the University of Birmingham, he evaluated the appeal procedure, and in other words, poked his nose into someone else’s business, which is why he had a fall-out with the manager of the HOP, and to make matters even worse, Director of the Muscular Dystrophy Society who has the power to decide who gets to live at the Home for Older Persons (there are only 13 rooms on the ward). Although it is unacceptable that a disability organization official decides who gets to live at the home, this is standard practice in Slovenia, and the Ministry of Labour, Family and Social Affairs are doing nothing to stop this. The welfare inspection hasn’t looked into the matter either. Because the HOP pressured our friend and tried to take control over his life, he requested for a price list of services offered to him. He wanted access to the list of services that Social Work Centres, the municipality, Health Insurance Institute and his own contributions pay for within the scope of his personal care and health care. Because he didn’t get that he cancelled his payments made to the home for older people at the bank. His debt was increasing as was the pressure to stop making complaints and recall the payment cancellation. Because they could not stop him as he is well-versed in writing complaints and an is expert in administrative matters and the General Administrative Procedure Act, the Centre of Social Work sent him a decision that he is unfit of making decisions for himself and that he has been provided with a caretaker, which meant that he lost access to his own financial resources. This was done without any kind of expert opinion or examination

or legal proceedings and he hadn't got a chance to defend himself. They did not state a reason for declaring him unfit either. He sent them all the possible appeals but was unsuccessful, although the decision hadn't been made final yet. In a state governed by the rule of law such matters are dealt with in courts and not by the Centre of Social Work, wouldn't you agree? After a week he was forcefully moved to another home, in the escort of the police; under whose jurisdiction? The Ministry of Labour, Family and Social Affairs was notified about this case and I sent them all the appeals that he had sent to the various institutions up to that point. Office for Human Rights and Office for Equal Opportunities were silent as well. There was an interview on television with this person, yet none of the numerous institutions, offices, bodies and inspection services, whose intentions are supposedly noble, made a move. The matter was slowly forgotten as were many other such cases. We do not expect much from disability organizations but we are disappointed with other NGOs.

3. Another example of discrimination that we will now turn to is the numerous revocations of memberships by the disabled persons society. The case of revocation of membership of five ex-members of Muscular Dystrophy Society is only the most recent one in the long history of such discrimination. The procedure was not carried out in accordance with the society's by-laws as the decision was not made by the Honorary Arbitration Board but by the Management Board, which means that more than half of articles in the social care code of conduct were breached: ethics, respect of human rights and liberties, acceptance of diversity, independence aid, mutual assistance and self-care, respect for the decision of an individual, right to information, respect of dignity, criteria of communication with the public and prevention of harassment and violence. The notice included no disclaimer or appeal period. Two out of three members of the management board of Muscular Dystrophy Society are also members of the Social Welfare Chamber, which has not responded to their appeals to this date.

3.a Article 14 of Social Welfare Chamber defines the following goals of the chamber: addresses appeals from Article 94 of the Social Assistance Act, regulates the execution of code of ethical principles of social welfare. The disability organisations united in SIOS were forwarding false data to the National Electoral Commission about the number of experts they employed for two whole terms. Based on this, the mentioned organisations had a greater number of electors than they should have, which is why Mr. Šušteršič was elected as the government advisor twice. You will probably agree that such practice not only breaches every code of conduct but is also a serious offence.

Individuals are unable to rebel against such abuse of power and arbitrariness. Although the Disability Organisations Act binds the Ministry of Labour, Family and Social Affairs to monitor disability organisations, complaints are processed only formally with documents that solve nothing. Violations are not looked into much less sanctioned whereas the process of revoking the permit of operation or the status of representativeness in the interest of the public, which is exactly why the Disability Organizations Act was drawn up for, has insofar never been put into effect. Individuals are waived their right to services and their basic rights are trampled. The disability organisations are formally defined as societies and thus do not fall under the law, which regulates public institutions. Formally they are obligated to provide their services both to their members and non-members, however, in practice things are completely different. Societies always find a way to waive one's rights to transportation, rehabilitation, assistance etc. All of this has never been sanctioned.

4. The fourth example of discrimination for which nobody wants to take responsibility is the violation of right to rehabilitation. Rehabilitation is carried out only by some disability organisations, by means of "public" tender and only people with certain diagnoses have the right to it, although it is supposedly a common right. On top of that, it is based on the "medical model", which is very telling.
   The plausibility of rehabilitation is not being questioned here, however, we do have a lot to say about its organisation, the policy of its organisers, as well as incompetence of the Health Insurance Institute (HII). Based on the principle of choice, every individual should be able to choose between several operators of these services but as it is now, the society signed an exclusive agreement, monopolizing the market of services intended for people with a common or similar diagnosis. HII did not form criteria to assess the quality of provided services as it performs no technical control and does not monitor the use of funds. It has no per-day service price list based on a given diagnosis, which is, of course, necessary when services are funded from state budget. People who actually need less resources and services therefore often get more than they need and vice versa, people who need more help do not get all the services they should. The price list is formed by the societies even before the "public" tender is made public. The HII lets the societies implement the services as they see fit and does not take measures even if expert opinions dictate that a certain individual needs a personal assistant. The HII thus allows for unearmarked use of funds, discriminates against beneficiaries who cannot use the services they are entitled to and violates internal acts and resolutions of the management board, as well as their own rules. Rehabilitation for persons with muscular dystrophy can not, for example, be implemented anywhere else but at Dom dva topola, owned by the manager of the Muscular Dystrophy Society. We do not know why is Dom dva topola more suitable than so many others and why did it get exclusive agreement for rehabilitation of persons with muscular dystrophy. Also, I am not the only one who does not wish to have rehabilitation at Dom dva topola.

4.a Muscular Dystrophy Society of Slovenia should, in accordance with the contract signed between them and the HII and in accordance with the HII's management board, provide its services to certain nine beneficiaries but refused to do so. They are trying to discredit us in all possible ways, their conditions are getting more and more absurd and apply only to us, they are making countless requests for additional documents, which are not taken into consideration when they are submitted (expert opinions that are not according to manager's expectations), they keep raising prices of their services so that we would have to pay more and are inciting their members against us. Rehabilitation that they have in mind is a pure case of socialist group thinking where you should consider yourself happy to get anything and where you have no right to request for anything unless you want to lose everything. That is where we are right now. What was once our right is now portrayed as a privilege of which we are supposedly trying to rob other more needy beneficiaries.

4.b . The director of the Muscular Dystrophy society does not have and should not have the right to decide who is entitled to rehabilitation because he is not taking into consideration even the medical opinions given by “his own” side. He has no right to chase ex-members from the office of the society in the time of office hours by repressive means (the police). He has no right to forward our personal information to the police officials. It seems wrong to us that an individual society, in our case the Muscular Dystrophy Society, has the power to influence basic human and citizen rights in the fields of social and health care. To make matters even worse, there is no control over how their funds are spent and the quality of the services they provide, even worse, nobody seems to want to take responsibility for that. Disability organisations are societies, which are subject to civil law and do not have to respect the laws and regulations that public institutions have to abide to, although they provide similar services and are funded by the state. They have access to personal information of their members and to the database containing information about one’s diagnosis (through the Rehabilitation Institute or the Institute for Neurophysiology) and they abuse this information for the purpose of discrediting its opponents. Inspectorate for Personal Data Protection was notified about these violations in 2000, 2002 and 2005 to no avail.

According to regulation acts of mandatory insurance regulations, a process for claiming the right to rehabilitation should have beee commenced by now. Its organiser acquires the right to financial funds for the purpose of providing rehabilitation based on a public tender. However, since organisers are societies, which are not public authorities, they are only formally obliged to respect constitutional and legal principles, which is not enough to ensure that individual’s rights are respected.

5. The next discrimination concerns employment. Association for the Blind and Hard-of-Seeing of Slovenia recently published a job advertisement for a social worker, which among other references and competences, also requires sharp sight. The ad was published on the Employment Office website. After we notified the Labour Inspectorate, the job application was altered and a penalty was imposed. However, we have noticed that the job application form issued by the Employment office includes a section “physical abilities”, with items such as, sharp sight, physical strength, manual skills etc., which makes it possible to discriminate not only against the blind and hard-of-seeing, but also against persons wearing glasses.

For a long time we have been wondering why NGOs do not take decisive measures to protect human rights in the case of disabled persons. Nothing happens although disability organisations and their representatives abuse their power against the individuals and when these institutions refuse to accept responsibility for their actions or do not comply with their duties and obligations nobody is not doing anything to improve our position. If we compare the public's response when other marginalized groups are discriminated against, it is obvious that we, disabled persons, get far less attention. Discrimination against homosexuals, immigrants, the Roma people, and the erased (people who were erased from the Permanent Residence Register in the early nineties) get much more media attention because this is the right thing to do and we are obliged to support them if we believe in equality of all people. These marginalized groups are supported by the various "anti-globalist" movements, peace groups, NGOs working in the field of human rights and social welfare, feminist organisations, intellectuals, artists etc. On the other hand, constitutional rights, independent living and the equality of the handicapped is something that supposedly concerns only the disabled and maybe also the Directorate for Disabled Persons at the Ministry of Labour, Family and Social Affairs. Inadmissible discrimination, violence and other violations against disabled individuals and groups are perceived as misunderstanding among the disabled and their organisations and struggle for financial gains. The "healthy", "normal" and "non-disabled" turn their heads away, saying they do not know who to side with (they never check the facts) and that the disabled should settle their differences on their own. Why is such treatment restricted only to the handicapped and why are e.g. asylum seekers who come to our country, seeking protection from their home country treated differently? I do not wish to prioritize discrimination or make certain kinds of discrimination more or less important; all I am trying to say is that I cannot understand why the public's response to the same kind of discrimination differs based on a group that is being discriminated against. Why isn't there more reciprocity among those who share similar values? Why doesn't an analyst, research journalist, columnist, intellectual or a humanist try to unravel the jumble of discrimination, physical, emotional and sexual violence against the disabled individual? No one dares to start a discussion on the various aspects and types of violence that disabled women are subjected to, although research done in Slovenia shows that the rate of violence against the handicapped committed by their family members, institutions and institutional staff and the broader environment is high. I would expect such a contribution soon and I hope to live long enough to read it, especially because it would push the discussion from the stalemate that we are witnessing right now. Due to all the things mentioned above, my writings are always reduced to the fact that I am disabled, a tiny woman (once I even heard someone use the phrase "baby girl"), that I am director of the YHD and that I can only write about the "disability topics". Every article that I have written so far was condemned as false and the editor or a journalist who I wrote the article for later received nervy calls and was attacked by disability organisations officials who waived EU declarations and representativeness statements at them. Every affair, protest or attempt to resolve violations and discriminations is thus destined to oblivion.

Our every-day observation is that although more and more rights are recognized on a declarative level, the actual state and standing of an individual does not reflect that.

The hardest to understand is discrimination by the very institutions that are supposed to prevent them and take measures against them should they arise. The organisations are often unresponsive and evasive or they bureaucratise processes to such an extent that the plaintiff loses motivation to press on. Due to ineffective and painstakingly slow legal proceedings, suits often fall under statute of limitation or the decision comes too late to make a difference. However, the most often used practice is to simply ignore the problem and the matter regarding discrimination against a handicapped person is shifted on the shoulders of the Ministry of Labour, Family and Social Affairs or the Directorate for Disabled Person, which merely sweeps the complaint under the rug. The Government Council for Disabled Persons does not do their job any better. The only mission that those bodies apparently have is to prevent and destroy any action that could bring about independent living, equality and freedom of choice for handicapped persons.

Author´s Address:
Elena Pečarič
Neubergerjeva 7
SLO-1000 Ljubljana
Slovenia
Email: elena.pecaric@guest.arnes.si