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# An Overview: International Human Rights and Mental Disability Law

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It is that last phrase, "the power of law to work for social advancement," that really represents the purpose of today's conference. At New York Law School we say that we learn law and take action. In thinking about that phrase it really does capsule the thought that has gone into the construction of our institution. Our students come to us with great conscious, with morals that they have been bringing to bear on their entire life. They join with faculty members who are wonderful, efficient practitioners and have great knowledge of the law; but it is the interaction between them that takes legal learning and applies it to do something that characterizes the law school to take action.

That is what you are about to see today in the symposium: learning about legal principles, learning about law, learning about the interaction of law in society. Not because it is an interesting subject. Not because the theory exists. But because it gives us the capacity to take action and do things that have value for other people.

Today I am quite pleased to be able to be a part of your attempt at taking law and using it to make a better world for all of us in the application of legal principles to very difficult problems. I know in looking at the panelists' backgrounds and looking at the topics that are going to be discussed, this will not be easy. There is no simple solution that can be found, nor will it be something that a mere prescription will lead to results for every possible situation, but the process of taking action, learning, making recommendations, applying them, coming back, and doing it again with greater precision and greater care, is really what learning law and taking action is all about.

So on behalf of all of us at New York Law School, thank you for coming today and thank you for listening. But more importantly, thank you for your active engagement in this very important field. I know, Michael, that you and your panelists will make interesting presentations today, and I cannot wait to see the written work. I know that it will be a spectacular attempt to bring justice to the world we live in.

Thank you every one and enjoy the day.

## **II. AN OVERVIEW: INTERNATIONAL HUMAN RIGHTS AND MENTAL DISABILITY LAW**

### **A. *"Chimes of Freedom:" International Human Rights and Mental Disability Law***

PROFESSOR PERLIN: Thank you very much, Rick. I appreciate it.

Before we start, I have some thanks. I want to thank Shani Darby, Sally Harding, and the people in the Office of Student Services who have made this happen. I am very grateful to you and to Alta Levat for the invitation and website, and Beth Berger and Jim Darling. This all came out of a chat I had with Beth Berger in a cafe over the summer. I have been at this law school eighteen years and nobody has ever done a job like Jim Darling. He is the consummate professional and every student should be extraordinarily proud.

I want to thank Rick for his total support for this and all the work that I did in this area, which is the mental disability area and Central Eastern European area. When I went to Rick last year and asked him whether Jean Bliss and Sara Rotkin could come with me to Budapest he said, "sure." For a professor to have a dean say "sure," just like that, does not happen all of the time. He encouraged me to put the conference together even though we flew in people from Budapest, Sofia, and other non-local places and for encouraging all of us to follow his total commitment to justice here and abroad, so thank you.

I am going to be speaking first and then I will introduce Èva Szeli and Krassimir Kanev on our first panel. Then the other panelists will continue on from there. What I am going to do is talk a bit about how I see what we are doing here today links-up with what we have been doing domestically in mental disability law for the last three decades.

For the past thirty years we have witnessed a revolution in American disability law, a revolution that has largely constitutionalized virtually every aspect of the involuntary civil commitment and release process, as well as most pressure points in the course of institutionalization, that saw developments in the right to treatment, the right to refuse treatment, the right to the least restrictive alternative course of treatment, that saw the first broad-based federal civil rights statutes enacted on behalf of people with mental disabilities, that saw the creation of a patients' bar to provide legal representation to such persons, and that, paradoxically, also saw both a ferocious backlash against forensic patients, especially, but not solely, persons found not guilty by reason of insanity, and a widening of the net that, by blurring the boundaries of civil and criminal mental disability law, has increased the categories of persons subject to the involuntary civil commitment power to now include those charged with certain sexually violent offenses and persons subject to assisted outpatient commitment.

It continues today, and there is no reason to expect any abatement in case law, statutory amendments, or advocacy initiatives in the coming years, and I am overwhelmed that my former students have gone into this as a career.

But it is a revolution that has largely been a parochial one. There have been important developments in other nations, both in common and civil law countries, but by and large this has been an American revolution and to some extent it is curious.

For the conditions that led reformers to launch a series of well-orchestrated attacks on institutional care and the involuntary civil commitment process in the United States certainly exists in other nations as well. If there has ever been any question about this the stunningly graphic and comprehensive report done by Mental Disability Rights International, "MDRI," a non-governmental advocacy organization dedicated to the recognition and enforcement of the rights of people with mental disabilities in Hungary, Bulgaria, Uruguay, and Mexico, eliminate any lingering doubt. Yet, for a variety of reasons there

have been few legal developments in these countries and others similarly situated that parallel what has happened in the United States over the past thirty years.

In the past two years, I have tried to make a modest change to this picture. Under MDRI auspices I have done a lot of traveling. I have traveled to Budapest, Tallinn, Riga, Sofia and to Budapest again, to consult with people, many of whom are in this room, activists, advocates, progressive mental health professionals, and with lawyers providing legal services to people with mental disabilities.

In Budapest, I spoke to members of the Psychiatric Interest Forum. In Tallin, I spoke to members and officials of the Estonian Psychiatric Patients Advocacy Association, in Riga, to members of the Latvian Center on Human Rights and Ethnic Studies.

In Budapest, I also met with the secretary of the National Disability Affairs Council, the secretary of the Hungarian Association for Persons with Mental Handicaps, and the head of the Hungarian Civil Liberties Union.

In Tallin and Riga, I met with law school students and faculty. Then in a later trip to Budapest I met with activists from Slovenia, Croatia, Kosovo, Poland, and other nations. In Sofia, I met with activists, lawyers, and advocates from some of these same nations as well as Albania, and I also worked with members of the Bulgaria Helsinki Committee, and for the first time a member of Amnesty International.

In each venue, I presented mini-versions of my two introductory mental disability law courses, stressing issues involving involuntary civil commitment, institutional rights, deinstitutionalization, and advocacy.

In Latvia, I also participated in a set of site visits to facilities for persons institutionalized because of mental disabilities. My aim in each case was to brainstorm with workshop participants in trying to figure out the optimal sort of ombudsman or advocacy project for each country and to see what sorts of problems were indigenous to those nations and which were global.

I wanted in each of these cases to be able to share our experiences so we could see how similar what we have faced in America is to what activists are facing in Europe. I don't know whether it will surprise you when I tell you that the pictures I saw this January from facilities in Bulgaria, horrible pictures of half-dressed patients in cage-like rooms, feces smeared on the wall, eerily reflected the conditions at Willowbrook State School in New York City when they were exposed to a nation some thirty years ago by the then-fledgling investigative reporter named Geraldo Rivera.

You can look at the pictures of Bulgaria and look at Staten Island and could not tell the difference between the two, only that thirty years have passed. Teaching in Central Europe taught me that how we treat people with mental disabilities in institutions and in the community is an international human rights issue and must be discussed, conceptualized, and taught in that

context. It was that experience that led me to think about the need for today's program.

There is something else I want to share because it is relevant, and that is the development of New York Law School's distance learning on-line Mental Disability Law Course. We have been doing this domestically for two years, since the fall of 2000, to lawyers, advocates, and mental health professionals.

We began last week doing a session in Tokyo, Japan, and we are now hoping and actively seeking philanthropic grant funding to allow us to expand and offer this program to an audience of activists and advocates from Central and Eastern European nations and elsewhere.

I tell you this now because I believe that a course like this may prove to be the most effective way of disseminating the important information that is at the core of much of the work that you will be hearing about from now until the end of the day.

What will this course do and how does it relate to today's program? I expect and hope, and I think that a Central and Eastern European section of the Internet course will satisfy these objectives: It would provide participants with firm grounding in all aspects of Mental Disability Law — institutional, forensic and private. It will offer them an opportunity to learn how the law on the books and law in action dichotomy — a gap that has been plaguing disability law for the last three decades — can best be resolved in an international context and will allow students to interact in a collaborative way to search for solutions of problems unique to Central and Eastern Europe.

The course mostly focuses on civil and constitutional issues, involuntary civil commitment, institutional rights, the right to refuse treatment, deinstitutionalization, criminal issues, such as the insanity defense, competencies, sentencing, sexually violent predator acts, the importance of mental disability in criminal trial process issues, such as confessions, and the privilege against self-incrimination, death penalty and torts law.

But I also included a section on advocacy and advocacy systems for our international courses, and I believe that this is especially important given our program today. Unlike the domestic sections, it also includes an advocacy training component tailored specifically for the needs of attorneys, activists, and advocates in Central and Eastern Europe.

I have included this additional material for several reasons. First, I am convinced after thirteen years of practicing law and eighteen years of teaching, that the presence of a vigorous and independent advocacy system with trained, specialized counsel is perhaps the most critical issue in determining whether any true mental health law reform is possible in any jurisdiction.

Second, there are multiple advocacy models, some of which may be more easily transportable to the civil law countries of Europe than others, and this component will help participants assess which models will work better in their nations. As an aside, I certainly do not believe there is necessarily a one size fits all model of advocacy for all the nations in Central and Eastern Europe.

Third, my earlier trips to the countries of Hungary, Estonia, Latvia, and Bulgaria clarified the importance of this issue to those who are likely participants in this course. Probably a majority of the questions that I was asked in all of the programs that I have participated in dealt with issues of advocacy models, ombudsmen projects, and issues like that.

Finally, I have written extensively about this issue in a domestic context, and I am eager to see the extent to which the conclusions that I have reached over the past three decades apply in an international setting.

Earlier I stated in summary fashion the objectives of the course. I think that is important to consider. Let me look the three principles that I am developing and see how that links up with today's program. We want to provide participants with a firm grounding in the substance of mental disability law. There is a remarkable overlap between the body of decisions that define American constitutional law and mental disability law and the body of international human rights standards that mandate humane treatment of persons with mental disabilities in every nation in the world.

Internationally there is a shameful history of human rights abuses in psychiatric institutions: the provision of services in a segregated setting that cuts people off from society, often for life, the arbitrary detention from society that takes place when people are committed to institutions without due process, denial of a person's ability to make choices about their life when they are put under plenary guardianship, the denial of appropriate medical care or basic hygiene in psychiatric facilities, the practice of subjecting people to powerful and dangerous psychotropic medication without adequate standards, and the lack of human rights oversight and enforcement mechanisms to protect them against the broad range of abuses in institutions. Mental Illness Principles approved by the United Nations can be used as a guide to the interpretation of international human rights covenants as they apply to people with mental disabilities.

In the case of *Victor Rosario Congo*, for example, the Inter-American Commission on Human Rights made this finding: "The United Nations Principles for the Protection of Persons with Mental Illness are regarded as the most complete standards for protection of the rights of persons with mental disability at the international level. These principles serve as a guide to states in the design and/or reform of mental health systems and are of utmost utility in evaluating the practices of existing systems."

Mental Health Principle 23 establishes that each state must adopt the legislative, judicial, administrative, educational, and other measures that may be necessary to implement these. These principles are also standards of assessment that makes international human rights monitoring by NGOs more possible.

Again, we will teach the basic aspects of all the major components of mental disability law, of civil and constitutional mental disability law, forensic mental disability law, and private mental disability tort law and try to illumi-

nate the parallels with international human rights law, a law that flows from the promulgation of United Nations standards, principles, treaties, and international court decisions in such away that participants will be able to most effectively integrate the substance of the law into the practice of the law and into the practice of mental disability law and mental disability advocacy in Central and Eastern Europe.

What about the law in the books and the law in action dichotomy? That part got me. There is a gap that has plagued American mental disability law since it began. Cases are decided on the Supreme Court level, yet are not implemented in the states. My students have heard me say this before. The United States Supreme Court articulates sophisticated doctrine, for example, mandating dangerousness as a prerequisite for an involuntary civil commitment finding, yet trial courts ignore that doctrine.

The Supreme Court issues elaborate guidelines to be used in cases of criminal defendants who will likely never regain their competency to stand trial, yet nearly thirty years later, half the states ignore these standards. This gap is a reflection of the level of pretextuality that permeates American mental disability law. By "pretextuality," I mean that courts accept, either implicitly or explicitly, testimonial dishonesty, frequently meretricious decision making, specifically where witnesses, especially expert witnesses, show a high propensity to purposely distort their testimony in order to achieve desired ends. This pretextuality is poisonous and it infects all the participants in the judicial system, breeds cynicism and disrespect for the law, demeans participants, and reinforces shoddy lawyering, blasé judging, and, at times, perjurious and/or corrupt testifying. As a result of this pretextuality the law on the books is often little more than an illusion and successful cases brought on behalf of persons with mental disabilities are often little more than just "paper victories."

Residents of Central and Eastern European nations are no strangers to pretextuality in many other areas of the law, and I hope through this symposium and this course, I can help participants identify the pretexts endemic to the mental disability law, and develop strategies for dealing with these pretexts in their work. By way of example, a recent analysis of the European Commission on Human Rights concluded that that body has interpreted the European Convention on Human Rights very restrictively in psychiatric cases. The cases analyzed in this article, cases that characterize the handcuffing of patients as therapeutically necessary, or that sanction the use of seclusion for disciplinary purposes, certainly bespeak pretextuality. We need to identify this and answer it.

Finally, we need to be collaborative. Many of the problems that are faced in Central and Eastern Europe are regional problems, ones that flow from decades of regimens that are often established and operate on a shoestring budget. I believe that an interactive program such as the one that I am describ-

ing provides the participants with an excellent and robust interaction in a supportive environment.

So how does this all link-up with what we are going to be talking about specifically today? Well, the hub of today's program is MDRI's report — a scathing report — of the Hungarian social home care report. That report exco-riates the conditions of the individuals in this facility and demonstrates the extent to which social reform efforts are needed. To plan a meaningful and potentially effective strategy it is necessary to consider all of the past efforts, some of which have been successful, some less so.

In the past three decades of practicing constitutional law in the United States, Hungary is not the only nation in its region in need of such social reform. You will be hearing of conditions in Bulgaria to which I have already alluded and how there is no overestimating the significance of this, and there are groups that have mobilized to meet that challenge. There is no way of measuring the significance of this.

Lastly, abuses of persons with mental disabilities are finally being considered as human rights abuses. Again, there is a parallel. It was not until 1972 that the United States Supreme Court in the case of *Jackson vs. Indiana* first held — that is the only case that I will cite — the due process course applies to the nature and duration of the involuntary commitment. It is inconceivable that this conference could have been held before that day, before the day that case was decided. It is only when we reach a consensus that abuses and institutions of persons with that commitment that a conference such as the one we are participating in today can be replicated in other nations.

Number three, I am convinced that although the problems in Central and Eastern Europe appear different than the problems in New York and New Jersey, it is essential that the constitutional developments that we have related over the last thirty years in the United States, developments that form the basis of much of the international law that you will be hearing about today, be contextualized for advocates and activists. I believe that the most cost-effective means of doing that is via an Internet-based course. Having said that, there are many other issues that need to be considered as well, issues involving court process, issues involving litigation, issues involving jurisprudence, issues involving the relationship between these human rights questions and broader political matters.

Each of these will be addressed within the context of today's program. Our program is divided into four main segments, each one moderated by a New York Law School professor, myself, Steve Ellmann, Sydney Cone, and Paul Dubinsky, and I am grateful to my colleagues for their help.

In the first panel Doctor Èva Szeli, Director of European Operations at MDRI's Budapest office, will speak to International Mental Disability Law, the Central and Eastern European experience. Doctor Szeli is a lawyer and psychologist and a frequent collaborator who, by the way, has traveled with me through the old town neighborhoods of Riga and Tallin on my never-end-



ing search for Bob Dylan rarities. She will discuss her work throughout the region as well as her work in Hungary, both on the social care home report and other initiatives.

Also, Krassimir Kanev, a human rights advocate with the Bulgaria Helsinki Committee will talk about International Mental Disability Law and Human Rights Law, the Helsinki Committee perspective, sharing with us the first important connections between the mental disability law movement and international human rights movement.

In the second segment, there are three speakers who are Dr. Katalin Peto, Eszter Kismodi, and Gabor Gombos, who is a psychiatrist, a lawyer, and an advocate for persons with mental disabilities. They will discuss the social home care report, what it says, how it came to be drafted, how the hands-on research was done, and what its implications are for other nations in the region. Then two New York Law School students, Sara Rotkin and Jean Bliss, both of whom accompanied me to Budapest last October, will present a report on that conference and how it gave life to advocacy ideals.

The third segment is one presentation and that is our luncheon speaker, Eric Rosenthal, who is the Executive Director of MDRI in Washington, D.C., and who is the one person in the world most responsible for meaningful human rights reform in psychiatric institutions in Central and Eastern Europe. Eric will speak on the application of international human rights law to institutional mental disability law contextualizing today's programs.

After lunch there will be four inter-linked presentations from four different perspectives. I have titled the afternoon session, "Bridging the Gap: American and Other Perspectives," in an effort to try to demonstrate how what we are talking about is related to a variety of other important jurisprudential, political, social and judicial perspectives. Professor Bruce Winick from the University of Miami Law School, one of the founders of the school of therapeutic jurisprudence, will speak on therapeutic justice perspectives on the questions before us. Professor Robert Dinerstein of American University Law School, one of the few American law professors who has done significant social reform work in this area of the world, will speak on guardianship reform perspectives.

Judge Ginger Lerner-Wren of the Broward County Criminal Court in Florida, who is the judge who sits on what is by all accounts the best mental health court in the nation, will discuss the court system's perspectives. Finally, Professor Elizabeth Duquette, who teaches at Northwestern Law School, will place this in a greater political context by speaking on European Union perspectives.

Finally, a word about my title, which is "Chimes of Freedom." As more than a few of you have already guessed there is a Bob Dylan connection. Don't worry; I am not going to sing. My title comes from, in part, Dylan's all-too-rarely heard masterpiece, "Chimes of Freedom," a composition that critic Robert Shelton has characterized as Dylan's most political song and an expres-

sion of affinity for a legion of the abused. The first verse of the song concludes: "Flashing for the warriors whose strength is not to fight. Flashing for the refugees on the unarmed road of flight. And for each and every underdog soldier in the night. And we gazed upon the chimes of freedom flashing." This is the first verse. I cannot think of a finer way of characterizing what we are discussing here today.

In conclusion, I want to say that this is not an easy effort. As you will learn from our upcoming speakers there is much resistance, much opposition, much more to do, but I am confident that eventually we will succeed because the importance of this enterprise is too important to ignore.

A revolution in mental disability law has changed the way we think about people with mental disabilities, treat those persons, and empower those persons. Trailblazing NGOs, such as MDRI, have changed the way we think about the relationship between human rights and mental disability law across the globe, and, not coincidentally, a change in technology has changed the way we deliver information, teach and learn.

We are going to hear today about developments in Central and Eastern Europe. I am confident that if funding becomes available for our Internet project we will be able to share information, ideas and creative solutions with other mental disability activists in Central and Eastern Europe in a cost-effective way. It will also dramatically increase the number of individuals who will have the capacity to provide grass roots advocacy in those nations and to restructure the practice of mental disability law and delivery of mental health services in that region of the world.

I have been involved in mental disability law for thirty years, but it is only in the past two years that I have been involved with international groups seeking solutions to international human rights-based issues and world peace issues. For the first time I feel that I have the capacity to "gaze upon the chimes of freedom flashing."

Thank you.

Our first speaker, other than me, is Èva Szeli who is MDRI's Director of European Programs. Èva is a licensed clinical psychologist and attorney specializing in legal advocacy for the human rights of persons with mental disabilities. She is a Hungarian-American raised with the language and culture of her immigrant parents and she joined MDRI in 2001 to establish a regional office in Budapest to expand its work in Central and Eastern Europe. Her work includes leadership in fact-finding missions and advocacy training workshops in Hungary, Bulgaria, Estonia, Kosovo, Latvia, and Russia. Èva.

*B. International Mental Disability Law: The Central & Eastern European Experience*

DOCTOR SZELI\*: Good morning. A few personal notes. Part of the idea for this conference came when Michael and I sat at a coffee house in Budapest last summer, and started talking about some of these important issues. As he spoke it struck me that I think this is the first time we have worked together in the United States other than JFK. This says a lot for my work there and also about Michael's involvement with MDRI. I really appreciate this opportunity that he has provided for us to showcase part of this work.

I want to make specific mention that I am particularly pleased to have Professor Bruce Winick here, who was a mentor of mine at the University of Miami, and is largely responsible for a lot of my work in this area. I also want to thank my boss, Eric Rosenthal at MDRI, who after countless phone calls, finally gave me the opportunity to do this work in a formal manner with MDRI, and to Gabor Gombos, the president of Mental Health Interest Forum in Hungary. It is their report that we will be showcasing today.

MDRI did a report in 1957 when PAV, did not exist. Since that time not only did the organization come to be, but it has done incredible work. It is a consumer controlled organization and is solely responsible for the presentation today in terms of this report, and although I went to Hungary to be in part of some technical assistance to PAV and Gabor, it is amazing that he became one of my most important mentors and I appreciate his presence here. Thank you.

I am going to do three things today. I want to talk about MDRI's work and then talk about three of the countries that we have worked in over the past year: Kosovo, Bulgaria, and Hungary. I am going to do a very quick overview of some of our work in those areas because I want to highlight the differences between some of the issues we are dealing with in these areas and some of the obstacles to mental health reform and international human rights in the area of mental disability that I have encountered working in Central and Eastern Europe. You are going to hear some familiar problems because there are similar problems that the United States has experienced in the past thirty years and is still struggling with. I want to address particularly some of the relationships between the United States mental health law and international human rights law in the area of mental disability.

First, I would like to tell you a little bit about MDRI. As I mentioned before, we are a non-governmental organization, which is sort of an international way of saying that we are non-profit. We are not connected to any state

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\* MDRI's Director of European Programs. A licensed clinical psychologist and attorney, she specializes in legal advocacy for the human rights of persons with mental disabilities. A Hungarian-American raised with the language and culture of her immigrant parents, she joined MDRI in 2001 to establish a regional office in Budapest to expand MDRI's work in Central and Eastern Europe. To date, Dr. Szeli's work with MDRI has included leadership in fact-finding missions and advocacy training workshops in Bulgaria, Estonia, Kosovo, Latvia, and Russia.

organization. We are dedicated to the international recognition and enforcement of the human rights of people with mental disabilities. Mental disabilities, in terms of the way we refer to them, include both individuals with psychiatric illness or those individuals labeled with psychiatric or mental illness, and also individuals who have been labeled with mental retardation or developmental disabilities.

Individuals that have been labeled with psychological disorders and those labeled with developmental disorders are generally mixed together in institutions. Coincidentally, a lot of the issues are very, very similar, despite the fact that service delivery is quite different for these two groups.

Why is this work important and what on earth are we doing in Central and Eastern Europe? This is actually something that is very important to me, and it comes fairly easy. I am Hungarian-American. I am very happy to be working in Budapest and really excited some of my organization gets to contribute to the work going on in the region.

But what is an American organization doing there? Interestingly, that question has been raised in less than kind terms over the past year or two. We have been called everything from imperialist to colonialist and all sorts of little names that I don't particularly appreciate. Nevertheless, I think it is a worthwhile question in terms of what exactly are we doing here and why aren't we cleaning up our own backyard. Why are we there and delivering a message that is still being delivered in the United States? Michael mentioned one of the reasons, which is that in the United States we at least have a thirty-year history of the start of the reform process in mental health. That process is just starting in many countries in the world and in Central and Eastern Europe. This is a particularly interesting issue because of the session which Elizabeth Duquette will be talking about this afternoon. There has been this impetus, this momentum, that has been going on in this region. There is plenty of work to be done and people ready to do it. There is a goal to be achieved. It is an area that is particularly exciting in terms of implementing reform.

You will see when I start talking about individual countries there are tremendous differences even among countries in Central and Eastern Europe in terms of where they are in the reform process. It is a particularly interesting area to work in currently because of the existing new developments. However, at the same time we need to be sensitive to cultural issues because, after all, the idea of importing a model from the United States to Eastern and Central Europe may not be the best way to go.

When I get up to speak in one of the countries we work in, one of the first things we say is, "I am not here to tell you how to do things. I am here to share our experience and share some of the knowledge that we have amassed in recent years and let you sort of figure out how this works and how it does not work." Also, I not only share the successes that we have had in the United States, but also the failures. The United States does serve as a sort of laboratory. We have done the experiments here. Some failed and some succeeded,

and therefore, that may in fact speed-up the process of reform in others countries because they can see some of the things that worked here and have not to figure out how to tailor that to their own country.

Next, I want to talk about the countries themselves, the countries where we work. I want to give you a taste of the type of work we did and the obstacles we have encountered in these countries.

We started working in Kosovo in the late summer of 2000. Although I had not been hired by MDRI at that point, I was working as a consultant with the organization. The work in Kosovo is different from the work in any other Central European group. First, it has not been recognized as a country, but it is a province with substantial autonomy, which is how the United Nations put it. Kosovo was interesting in the news in 1998 and 1999, but we have not heard a lot about it since then, yet it has been under United Nations administration ever since the NATO initiative. Ever since then it has been the United Nations that has been responsible for the day-to-day administration of the province. That includes everything from routine types of things, such as garbage collection and basic municipal administration, which now is gradually shifting over to local administration, to being responsible for institutions, such as the ones that we are talking.

MDRI does two primary things. One of them is fact finding. We go in and look at what the conditions are inside institutions. We look to see whether human rights standards are being met in the way standard services are delivered or not and advocacy components. So the institutions that we are particularly concerned about in Kosovo, for example, there are two primary ones — and hospital wards as well — were ones that we went to look at to see exactly what the conditions were. How do people live in these institutions? And what type of human rights were violated. We found a lot of violations, but this is different than any other country we worked.

It is not the government, it is the United Nations that we are holding accountable for these abuses. It has been a particularly interesting and difficult work for us in terms of having to deal with the United Nations as overseeing the system that we have found significant abuses, such as physical and sexual abuse in institutions, to basically civil commitment protections that are being gutted by the bleak guardianship system. You can have the most beautiful civil commitment law in which theory protects individuals, but if you have no guardianship law that protects people's rights under guardianship, and there is no civil commitment law, the protections don't mean much.

One of the most important things about our work in Kosovo is that there is a wonderful and rich history of grass roots advocacy. Why? Because for ten years, between 1989 and 1999, they were in a period of marginalization. When people came in and the Belgrade run system replaced all systems in the Kosovo province, people were simply set aside. You went to work in the morning and were told you had no job, that they were putting a Serb in your position, so go home and that is it.

So in all of this health care, education, and politics, the Kosovars were simply pushed aside and Serbs replaced them. This whole parallel system developed of grass roots work that really is an incredible resource in Kosovo that we tapped into.

What has been missing there is stakeholder administration. By "stakeholder" we mean people with an interest, people with a stake, who are those people with diagnosis of mental disability and their family members. Progressive mental health professionals also have a stake in advocacy. Stakeholders fuel reform and we try to support that.

In Kosovo there is a complete lack of any significant type of oversight and monitoring in terms of overseeing and reporting these abuses. Reporting them has to be fueled by people with true interest, true experience, and true knowledge about what it is that people go through when they are in institutional life. What kind of abuse happens and what kind of undignified inhuman types of practices go on in the institutions? Some of them have been of particular concern in terms of the lack of the United Nations to tap in and to directly address these issues.

One of the additional issues that we had a really hard time convincing people in Kosovo is this whole issue of human rights and mental disabilities, and trying to put these two things together. A very common comment we get is, "Yes, we are a human rights organization. The United Nations obviously has an interest in human rights." You think you are preaching to the converted, but you are not because what you get from United Nations organization and other NGOs and private sector organizations that do work in this area is well, mental disability. We do human rights. We don't do mental disability. This has some fairly problematic connotations.

First of all, mental disability is not subsumed under human rights. Also, there is the whole issue that these are the individuals that are most vulnerable to human rights violations because they are the most stigmatized. They are set aside and the institutional care which is delivered to them is delivered in a place where society would prefer to forget exists, and therefore, they are more vulnerable to the type of abuses we are talking about. The full Kosovo report is expected out in the next few months.

Krassimir Kanev and I have been working together since last fall, we did two fact-findings, and went to do a conference in Sofia.

Bulgaria, in contradiction to Kosovo, is different. Kosovo has had lot of resources, but they are starting to wane because Kosovo was interesting. It was a sexy place to be a few years ago. Everybody wanted to go there because it was current event news. Money, resources, and expertise flowed in and we are disappointed that more basic practice models have not been implemented in Kosovo.

In contradiction, Bulgaria is a fairly poor country. Financial resources are low everywhere. It is very difficult when the general standard of living is fairly low, to try to convey to this particularly marginalized group that their

standard of living needs to be up to the general population. Some of the abuses that we saw, that Michael mentioned in terms of Bulgaria, are the worst in many ways that MDRI has ever seen.

We saw people, women actually, in cages — literally — metal structures attached to a concrete wall where six women, half clothed in horrifically filthy conditions were placed because they were “dangerous.” They didn’t look particularly dangerous to us when we saw them and, of course, if an individual is dangerous you would assume they would not put six of them in one place together. The good news is that this no longer exists because of action by Amnesty International which has gotten involved.

We also went back and found an institution where a woman was chained to a wall. We asked about that and they said, “Well, we don’t do it as a choice. We did get some extra resources last year so we built a little prison cell room.” They were very proud of a room with three prison cells, probably five feet by ten feet, with three individuals in these cells, none of whom met any conditions for seclusion restraints, even actually involuntary commitment. These people were placed by guardianship, which is a human rights issue because in the name of guardianship you can do anything and violate any human right.

They said the reason a woman was chained to a wall was because they needed more of these rooms, and asked us if we could help them get the funding. Your heart sinks when somebody asks you a question like that because it conveys two things. One is that these rights are clearly being abused. The other is that they do not know or understand that. That is the level where some of this work happens. Where the individuals that are in power are not evil, they just don’t know. So a lot of this has to do with getting people to understand how damaging this is. The fact that there are various fundamental human rights that are being violated was particularly disheartening.

Children in Bulgaria were particularly a concern for me because it is very clear that in a system like that, once a child enters the system at the level of institutionization for children, for example, there is only one way out and that is the end of the road. There is one way out, to die. When you see a six year old with a slight mental disability, or even just abandoned, end up in this institution, you know this child will never get out. This child that you are seeing will end up in one of those awful places that we visited for adults and will probably never get out. So that is a particular problem in terms of some of the Bulgarian issues we dealt with.

The other issue in Bulgaria is that there was a lack of professionals. For example, with the primary psychiatric organization, a professional organization, there was an unwillingness to take a clear stand against these issues. There is this uncertainty in terms of how or what they should do. They have political concerns about taking a stand and this was particularly disturbing because some of the practices are so clearly in violation of international human rights standards and of professional standards. The clearest is unmodi-

fied ECT, electric shock therapy, which is used in the United States. Unfortunately, the fact that it is still used in the United States is cited to me often. They say, "It can't be bad because you use it." I have to clarify that I do not represent the United States or condone the use of it. But they use unmodified ECT with no anesthesia and no muscle relaxants. We may still use it here, but that is a particularly barbaric way of using it. That clearly is not used here and should not be used anywhere. Even on something like this professionals are wavering on whether to take a stand against this practice, and I think it is important.

For me, one of the most important messages to convey, for example, to a professional organization like this — and I don't mean to single out Bulgaria, but it is just one of the places we worked — is that there is a fork in the road for a professional because at this point you can become part of the problem or part of the solution. Really what happens is that if you refuse to take action, you end up being an obstacle.

Psychiatrists have been vilified in the mental health process in many ways. Unfortunately, in advocacy there are a few psychiatrists as progressive mental health professionals. One of the warnings I delivered in Bulgaria was, "This is your chance to break free. This is your chance to rather than be part of the obstacle to be a lead in the reform process." That is important because you meet mental health professionals who say this is not the way I want it to work; I know it is wrong. There are professional concerns, like their own job security and professional status, and it takes an incredible amount of bravery to stand up against them. We are not talking about Hungary. We have Doctor Hugo Pat with us, a doctor from Hungary, who took a stand in Hungary that is important and admirable as far as Bulgaria is concerned.

I want to echo what I said about Kosovo, about stakeholder advocacy as an important aspect of the process. It is part of the reform process that has not started yet in Bulgaria, but needs to start getting people directly affected, involved, and getting them to voice their concerns and move the process along in the direction that it needs to be moved in.

The wonderful analogy somebody gave me was, imagine going to a women's rights conference and it is all men and they are saying women need more rights and they are sitting in the abstract. This is what it is about. We don't think about that in mental disabilities. A room full of people get together and talk about what should we do about the rights of these people. Well, where are these people, and why aren't they here? Why aren't *they* expressing what needs to be done? When it comes to women's rights, ask the women. When it comes to mental disability, ask the people labeled mentally disabled. That is the way to make change.

In terms of Hungary, it has been one of the countries in which MDRI has worked the longest. MDRI's work in Hungary started in the mid-90s. I was not with them back then, but I became involved later on, so I feel like collectively it is our work. We came along in the mid-90s and the visible abuses



were much worse. The primary ones that are in the 1997 report on Hungary, which is currently being updated and will be released in the second edition this summer, the important aspects about this was that bed cages were used in Hungary. They are pretty much what they sound like, cages built over beds. They are locked. They prevent people from getting out. This was discovered by MDRI during our work in the mid-90s and basically that was the big scandal of this particular report.

The good news is that there has been progress in Hungary. For example, the usage of bed cages has decreased. The bad news is there is still no legislation prohibiting use, so they are being used and the individuals that use them don't understand how to get along without them. There is progress in terms of physical conditions. It is quite a contrast to me because I had been to Bulgaria in January and the conditions are so barbaric and medieval that I go to Hungarian institutions where the institutions are clean, they are brand new, everything is newly painted, the furniture is new, everything is just bright, sparkling, and you look around and say, "Wow, this is not so bad."

Now the problem with that is that getting human rights abuses identified in some ways — and this is incredibly ironic and I want to be sure that I am not misunderstood — it is almost easier in Bulgaria because you show photos and there is no way to say this is not a human rights abuse. You can't put people in cages. You can't chain them to walls. You can't let them live in these filthy conditions.

In Hungary the challenge is different. It is subtler because there you are saying, "This is beautiful. This is really nice." Some of these institutions are far out in old castles with beautiful grounds. You would love to walk around in this area, but I have to tell you, you would not want to live there. Why? Because look about your day, the places you go and the people you interact with. Think about one place far removed from civilization and it is the only place that you ever get to go, the only people you get to see is them. You have no schedule, no freedom of choice with anything that matters.

That, as a human rights abuse, is harder to point out and change because people point to what things look like rather than what is going on beneath the surface. So the challenge is really community mental health care, which right now means let's build small, protected apartments on the grounds of the institution. We have community mental health and it is not about that. It is about integration.

The reason institutions exist is because we discriminate. We basically say individuals that have been labeled with mental disabilities deserve something different, in fact, something less than everybody else deserves, and so these institutions exist because of that. But discrimination will continue until you integrate people and bring them into society and put an end to the segregation that discrimination will always be reinforced.

Thank you.

PROFESSOR PERLIN: Thank you so much, Èva. That was wonderful.

Now I am very pleased to introduce our next speaker Krassimir Kanev, who is really one of the most remarkable people I ever met in my life. He is with the Bulgaria Helsinki Committee.

On the table outside in the hall you will see a copy of a report of inpatient psychiatric case in Bulgaria and human rights, a sixty-plus page report which he was largely responsible for. Whenever I have dinner with Krassimir there is always an interruption when a TV reporter will come and ask him questions, not only about mental health, but I have the sense that he is the single expert in Bulgaria on absolutely everything, and I am happy and pleased that he came here today.

Krassimir Kanev will talk about mental health in Bulgaria and he is going to talk also about a very important decision in the European courts called Vurbanov versus Bulgaria and he is going to talk about standards of the European Committee for the Prevention of Torture which is sobering, but a title we need to think about. I am pleased to introduce Krassimir Kanev.

*C. International Mental Disability Law and Human Rights Law:  
The Helsinki Committee Perspective*

MR. KANEV\*: Thank you, Michael.

Before I start, let me say how pleased I am to share my experience today with all of you, and how grateful I am to the New York Law School for having invited me here.

As Michael said, I work for the Bulgarian Helsinki Committee as director of the organization. I am also a member of the Executive Committee of perhaps the biggest European human rights organization, the International Helsinki Federation for Human Rights, based in Vienna. The work of BHC on mental disability rights started out in 1994. At that time we visited several institutions and produced our first report, a report that dealt mostly with the inpatient psychiatric care in psychiatric hospitals. Then later, we expanded on social care homes, on homes for mentally disabled children, and at this point we are in the process of reviewing the entire system, and the report that is already finished is the first in a series of reports that we are going to produce on mental health or mental disability rights. The first report is an overview of the inpatient psychiatric care only in the psychiatric hospitals, only in institutions for active treatment of patients.

In addition to our monitoring work — and this monitoring work is a work that we do together with several other organizations in Bulgaria including the Bulgarian Psychiatric Association — we also litigate cases, both domestically and at the international tribunals. In October 2000, the European Court on Human Rights decided its first of cases brought from Eastern Europe, the case

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of *Varbanov vs. Bulgaria*. It was brought by our organization. This was a case of a person arbitrarily and unlawfully confined to a psychiatric hospital in violation of the due process guarantees that the European law established with respect to the civil commitment procedure.

Three weeks ago we reached a friendly settlement with the government on the case of another person that we defended, another ex-patient who was, again, unlawfully and arbitrarily chained in a psychiatric hospital in violation of the due process standards. In this, as well as in the *Varbanov* case, the European Court on Human Rights held that the Bulgarian law on its face is in violation of the standards of the European Convention and that it needs to be substantially reformed. I heard three days before I came here that the government of Bulgaria has started this process of reforming the law on civil commitment. This, unfortunately, is not going to be an overview of the entire legislation on mental health that certainly needs to be reviewed. This was what I wanted to say about Bulgaria. The topic of my talk today is international mental disability standards and human rights law.

Today I want to make four points drawing on our experience with litigation and on our attempt to apply these international standards and international law as applies to mental health issues.

First, that international mental disability standards are not developed as a law. They exist for the most part only as non-legal standards at the United Nations and Council of Europe level.

Second, that mental disability standards are not always consistent.

Third, that international human rights law deals with a very narrow scope of issues which is only a small part of international mental disability standards.

Fourth, international human rights law is not consistent with these standards and there is a need for mental disability law with effective enforcement and for the incorporation of mental disability standards into the international human rights law.

Let me now elaborate on these four points that I have made. First, on the nature of international mental disability standards. As we all know, there is at present no comprehensive United Nations or other international treaty dealing with the rights of the mentally disabled or with the discrimination against them. If we compare this situation with the situation in many other spheres such as the prevention of torture, racial discrimination, discrimination against women, rights of the child, we will see that this compares very unfavorably to the developments in these also very important fields. What we have now, and what we have tried to use in Eastern Europe, are the UN Principles for the protection of persons with mental illness adopted by the General Assembly resolution 46/119 in December 1991. They are perhaps the most elaborate mental disability standards so far developed. I would not say there is something more comprehensive at the regional level than United Nations principles. Then we have at the UN level the Declaration on the Rights of Mentally Retarded Persons from December 1971. Also — a rather elaborate set of United

Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities from 1994. These are dealing with the disabilities generally, but are also very appropriate and very useful tools to apply in the case of mental disability.

At the Council of Europe level we have Recommendation 1235 from 1994 of the Parliamentary Assembly of the Council of Europe on psychiatry and human rights. Then we have Recommendation R(83)2 from 1983 of the Committee of Ministers of the Council of Europe concerning the legal protection of persons suffering from mental disorders. And last but not least, the most elaborate of the Council of Europe standards, those of the CPT or the European Committee for the Prevention of Torture and Inhuman and Degrading Treatment or Punishment. These were standards established in the CPT country report after visits to psychiatric establishments and summed up in its 8th General Report.

This is all not law. This is all "soft law" at best. It is in many cases internally inconsistent and something that cannot be used domestically and internationally for litigation in the international tribunals. When I speak about inconsistencies I will just mention several issues that are important in that regard.

Let's first talk about inconsistencies in the international mental disability standards. For me, for instance, a very serious problem with the United Nations principle is the application of the limitation clause. It provides that the rights set forth in the principles for the protection of persons with mental illness may be subject only to such limitations that are prescribed by law and are necessary to protect the health or safety of the person concerned or of others, or otherwise to protect public safety, order, health or morals, or the fundamental rights and freedoms of others. This is a rather vague limitation clause to me, and in addition to this vague provision, some of the United Nations principles are in fact not clear in many of the rights and freedoms they provide for.

Another problem with the United Nations principles is the 11.15 principle allowing for the possibility to carry out clinical trials on incompetent people, although under certain very special conditions. Then on seclusion and restraint we have a number of controversial standards. In Recommendation 1235 of the Parliamentary Assembly of the Council of Europe mechanical restraint is prohibited. That is what paragraph 7.1.b. says, that any mechanical restraints should be forbidden. They are, however, not forbidden either by the United Nations principles or in the CPT standards. They both provide that in certain exceptional conditions mechanical restraints could be used. A number of officials have pointed this out to us: Well, we restrain people, so what? United Nations principles allow this. CPT allows this. They say you could do this in exceptional cases, and we do this in exceptional cases. The United Nations principles do not say what circumstances are exceptional, and neither do the CPT standards say what circumstances are exceptional. We found in one hospital — this was a small hospital, with a little bit more than one hun-

dred patients — that for two months there were thirty-eight people mechanically restrained. The staff said these were all exceptional circumstances.

Another inconsistency is the right to seek a second medical opinion in cases of involuntary admission. This is provided for by Principle 16 of the United Nations principles, but there is no such right at the CPT level. Another problem is the right of informed consent to treatment. CPT standards on this are much stronger than the standards of the United Nations principles. All these inconsistencies in international standards are an indication that this is an area that is developing and it is in a very rudimentary state.

Let me now talk about the international human rights law. How do the international mental disability standards compare to it and what is actually the substance of international human rights law related to mental disability?

At both the United Nations level and the Council of Europe level we have two very vague provisions that allow for the detention of persons of unsound mind, e.g., Article 5 of the European Convention on Human Rights.

The European convention was developed back in 1950 and this provision was supposed to allow for the detention of those who are of unsound mind in general. It was only later — thirty years later, in September 1979, when the European Court of Human Rights in the case of *Winterwerp v. The Netherlands* developed standards on how this provision is to be applied. And when developing these standards the European Court on Human Rights narrowed substantially the scope of application of Article 5.

It ruled three things: that persons must be shown to be of unsound mind by medical experts; that mental disorder must be serious and warranting compulsory confinement, which means that everybody who wants to detain anybody for whatever mental disorder must show that the person is a danger either to himself or herself or to others; and, that the detention must be validated by the presence of the disorder and its persistence. In other words, the person should be discharged immediately when there is no reliable data that he/she is mentally disturbed.

Other areas that potentially and actually were covered by the international human rights law with regard to mental disability standards include — and this is perhaps the area which was most litigated at the European Court of Human Rights — the procedural safeguard. The European Court applies the safeguard elaborated in Article 6 the European Convention to the judicial review of the civil commitment under Article 5.4 of the Convention. It established clear rules on what the procedural standards in commitment should be. In the recent case of *Magalhaes Pereira v. Portugal*, the European Court established that in any case of civil commitment, the committed should be effectively represented by a lawyer. In cases where the person cannot pay for the lawyer he/she must be assigned somebody who is sufficiently qualified. Actually, the person who was committed in the Portuguese case was himself a lawyer. He also had an ex officio lawyer appointed who didn't do much for

him. Nevertheless, the court ruled that if the person is not sufficiently qualified he should be assigned an effective lawyer.

Then there were a number of ECHR standards dealing with the possibility to appeal the commitment to a higher court. This was, as I said, the most elaborate case law of the European Court of Human Rights. There is a case law at Strasbourg indicating that the European Court could have been involved in adjudicating cases of mentally ill people on their conditions of detention. There was no actual case brought to the European Court of Human Rights on the conditions of detention in psychiatric institutions, but a number of other cases were brought by litigants who had been imprisoned or detained in other detention institutions from which we can judge that this is an area which the Court would be willing to look into with regard to psychiatric institutions as well.

One potential area of litigation is the issue of informed consent, although, again, there were no cases on this before the European Court. This is potentially an issue that can be adjudicated under Article 8 of the European Convention. Perhaps some inhumane method of treatment can also be brought to the European Court, such as the use of unmodified ECT. We have singled out such cases that we would like to bring under Art 3 of the European Convention, which prohibits torture, inhumane and degrading treatment and punishment, although we don't know how lenient the European Court can be to the treatment methods.

So this is all that is actually the scope of the human rights law relating to the international mental disability standards and this is a very narrow scope. Lots of things that we find in the United Nations principles for the protection of persons with mental illness we do not find in the jurisprudence and in the text of the international human rights law.

There is no right, for instance, of treatment in community or in the least restrictive environment, no right to independent review of some specific forms of treatment, no right to second medical opinion, no right to exposure to a variety of treatment methods.

There is no obligation to report treatment methods, and especially some of them like the ECT and seclusion and restraints. All of this is lacking and all of this is something that cannot be litigated at an international tribunal because there are no standards.

The jurisprudence of the international tribunals is sometimes inconsistent with some international mental disability standards. For instance, in the case of *Varbanov v. Bulgaria*, the Court established that Mr. Varbanov, the litigant, was tied to his bed at night for a prolonged period of time, which is apparently inconsistent with the CPT standards, but this was not regarded as a violation of Article 3, as inhumane and degrading treatment, an inconsistency of the jurisprudence with the international mental disability standards.

My last point is on the need for international mental disability law and we have some encouraging signs of this from the United Nations. Why do we need comprehensive international mental disability convention?

First, to cover the gaps and to remove inconsistencies of which I have already spoken.

Second, and probably most important with respect to the situation in Eastern Europe, to introduce reform in the legislation and in the practice of a number of countries. These are countries that do not have local societal resources to undertake a comprehensive reform of their legal system and to adapt them to the requirements of the international standards. There is no favorable public opinion. The only resource for reform is international indictments in one way or another. The fact that the Bulgarian government knew, for instance, that the Bulgarian law is inconsistent with the norms of the European Convention of Human Rights back in 2000, when the first case was decided, but accepted to review the legislation only when a second case was on its way to be decided by the European Court, is very indicative of where this reform can start from and where the driving forces of this reform can be.

Last, but not least, we need a comprehensive international mental disability law in order to empower patients and better protect their rights, not only at the domestic level, but at the international level.

Thank you very much.

### III. HUNGARY: THE SOCIAL CARE HOME REPORT

ASSISTANT DEAN ELLMANN\*: I would like to welcome every one to the panel on the Hungary Social Care Home Report. My name is Steve Ellmann. I am an Assistant Dean and professor here, and I was also, long ago, a mental health conditions litigator. It is a privilege for me to come back to these issues and moderate this panel. We have five panelists, a distinguished set of folks, three from Hungary and two from New York Law School.

Let me say a word about them and we will start. The first speaker will be Gabor Gombos, the president and founder of Hungary's Mental Health Interest Forum, the source of the report that we are about to discuss.

He will be followed by Dr. Katalin Peto, a psychiatrist and vice-president of the Mental Health Interest Forum who currently works in an out-patient clinic for psychiatric patients.

The third speaker is Eszter Kismodi. She is a lawyer, a legal advisor to the Mental Health Interest Forum, and is an LLM candidate at the University of Toronto Law School. The fourth and fifth speakers are Sara Rotkin and Jean Bliss, New York Law School students.

Welcome.

This is Gabor Gombos.

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