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THE APPLICATION OF INTERNATIONAL HUMAN RIGHTS LAW TO INSTITUTIONAL MENTAL DISABILITY LAW

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turning up the volume in a concerted and cohesive effort, educating those who still may stand under the shadows of sanism, all the while stressing the concepts of dignity, liberty and self determination, that is what I would call an ideal form of advocacy.

Thank you.

ASSISTANT DEAN ELLMANN: I want to thank all of the speakers who had to say so much in a relatively short period of time. I can't resist saying that this panel reflects and this report reflects something that when I was doing this kind of law twenty-five or thirty years ago didn't seem anywhere near or true and that shows the tremendous value of the perceptions and the work of users of advocacy.

I am very struck by what you all have done. On that note we are done with this panel.

IV. THE APPLICATION OF INTERNATIONAL HUMAN RIGHTS LAW TO INSTITUTIONAL MENTAL DISABILITY LAW

MR. CONE*: Eric Rosenthal is the founder and Executive Director of Mental Disability Rights International. On behalf of MDRI, Mr. Rosenthal has trained activists in sixteen countries and investigated human rights conditions in psychiatric institutions, mental retardation facilities, orphanages, and prisons in thirteen countries. He is the primary author of MDRI reports on Mexico, Russia, Hungary, and Uruguay, as well as academic articles on international rights protections for people with mental disabilities. As a recipient of the Humanitarian Award of the Mental Health Association of New York City in 2001, Mr. Rosenthal was commended for his exceptional dedication and leadership in advocating for the humane treatment of people with mental disabilities worldwide. As a consultant, Mr. Rosenthal has served the World Health Organization, the United States National Council on Disabilities, the United Nations Special Reporter of Disabilities, and UNICEF.

Mr. Rosenthal received his law degree from the Georgetown University Law Center in 1992 and his BA from the University of Chicago in 1985. He has had a number of fellowships and it is an honor to have Mr. Rosenthal here, and I know that we all look forward, and I know that I look forward, to hearing his comments.

MR. ROSENTHAL*: Thank you very much.

* Sydney M. Cone, III is the C.V. Starr Professor of Law and Director of the Center for International Law at New York Law School and Of Counsel, Cleary, Gottlieb, Steen & Hamilton.

* Eric Rosenthal is the founder and Executive Director of Mental Disability Rights International ("MDRI"). On behalf of MDRI, Rosenthal has trained activists in sixteen countries and investigated human rights conditions in psychiatric institutions, mental retardation facilities, orphanages, and prisons in thirteen countries. He is the primary author of MDRI reports on Mexico (2000), Russia (1999), Hungary (1997), and Uruguay (1995), as well as academic articles on international human rights protections for people with mental disabilities. As a recipient of the Humanitarian Award of the Mental Health Association of New York City in 2001, Mr.

Thanks to New York Law School for inviting me here and putting on this amazing day's events for the students of the *Journal of International and Comparative Law*, who I know have done so much work to make this possible, and to Professor Michael Perlin, whose vision it was. It has been a pleasure to collaborate with Professor Perlin over the last number of years, and he has thrown himself into this, generating ideas faster than we are able to keep up with. If we keep up with half of his ideas we are doing a good job, and there are many exciting events and opportunities for collaboration.

As I look around the room, I see so many people who have contributed in so many ways to the work we have been doing in Hungary. It has been a pleasure to work with them and others. Dr. Humberto Martinez is a psychiatrist from the South Bronx Community Mental Health Council. He is co-author of our first report on Uruguay and Mexico. Wendy Rothstein has been an important supporter. She has helped us make contact with activists and service providers doing cutting edge work in New York City. Henry Dlugacz, a former student of Michael Perlin, traveled to Mexico on behalf of MDRI to train activists. The number of ways in which these people and this symposium has come together is tremendous. It is a pleasure to be here.

In order to understand the development of the international disability rights movement, I would ask that you step back with me, ten years ago, to the time when I founded this organization. I would also ask you to look back fifty years ago to the foundation of the International Human Rights movement after World War II. We must look at how far we have come because it allows us to see the tremendous progress that has been made in a very, very short period of time. As we do so, we can envision where we may be ten and fifty years from now.

I would also like to take the question that Èva Szeli raised in her speech this morning. So many people ask, why do we do this work? When we travel abroad, we are often asked: Who are you as Americans going around the world looking at this problem when you have so many problems at home? It is important to recognize that we have serious problems at home and there are enormous abuses in the United States. Yet, I would like to flip the question. Why did it *take us so long* to do this work?

This is an international human rights movement, and one of the core concepts of international human rights is that there are minimum norms that apply universally. There are certain minimum standards of behavior by governmental authorities that should never be broken. When governments violate the rights of their citizens, the world will speak out. We are on firm ground when we hold governments accountable for subjecting their own citizens to inhumane and degrading treatment or torture, for example, or when they arbitrarily detain their citizens, or subject them to systematic discrimination.

The international human rights movement is new. We must remember that the international human rights movement was founded after World War II, when the world learned about what governments could do when they turned against their own citizens. When the world learned about the holocaust, we asked the question: Why did we not speak out more loudly when the Nazis put the Jews in the concentration camps, the gypsies in the concentration camps, or when they carted off people with mental illness to hospitals or concentration camps to be killed?

The international human rights movement is about the principle that we must say "Never again." We are going to speak out when fundamental human rights violations take place anywhere in the world. The question should not be, "Why are we meddling in the affairs of other countries." The question is, "Why did it take so long when it comes to human rights abuses in the name of mental health care?"

After ten years of this work, I have done investigations in thirteen countries and worked with activists from far more countries than that. The work of Mental Disability Rights International has found that human rights abuses against people with mental disabilities are a pervasive, worldwide problem. We have published reports on human rights abuses against people with mental disabilities in Mexico and Russia. We have done work in other countries in Central and Eastern Europe. In every country that I have visited, we have found pervasive discrimination and abuse of people with mental disabilities. In almost every country of the world that I have visited, children with disabilities are excluded from schools. Adults with disabilities do not have public accommodations. They cannot participate in public affairs. Many of them cannot partake of the public benefits on which other citizens rely. In any society that discriminates in public spaces, you will find that there are also dark, closed spaces where people are placed by medical, psychiatric, or social welfare authorities. These are the dumping grounds for people who do not fit in or are not wanted. In some societies, unfortunately, like our own, the dumping grounds may be our own streets. In other societies, the stigma of mental illness or other disabilities is so great that people are literally closeted in their homes. We have heard stories in many areas where people with disabilities are never let outside of their homes. They are literally locked in for ten, twenty, or thirty years. Family members are so ashamed of their relatives with mental disabilities that they never let them out of their homes. Sometimes this is not the family's fault. Discrimination in the community can mean that going to the store, getting a job, or walking down the street is difficult or dangerous. In addition to the suffering of the one locked-in, the lack of opportunity to participate in society at large often means impoverishment for the whole family. Ironically, the people that might contribute to their family or to society at large to help end that impoverishment are never given a chance to do so. We are all the poorer for their lack of participation in society.

I am going to focus today on the common problem of people being segregated from society more actively by medical or social programs that place them in institutions. The abuse of people detained in psychiatric facilities and orphanages is what you have heard about from other speakers today. Ten years ago, MDRI started to document the human rights abuses of people with mental disabilities, and has since brought the problem of abuses in psychiatric facilities to world attention. It is one of my great pleasures that ten years after we started this work, I can now come to a conference where I can sit in the back of the room and fold my arms and listen to activists like those in Hungary doing the work themselves. They are now the ones documenting the abuses. They are the ones holding their own governments accountable. This is the way it should be. Ten years ago, many of these activists were already doing this work, but so much of it went unappreciated and unrecognized. They have gained strength over the years.

When I first went to Hungary ten years ago, I met Gabor Gombos. We met in someone's living room, a small ragtag group of people who never received international recognition or support for work they did. The world was not yet looking. They were fighting a good fight ten years ago. In so many countries I have visited in South America, Asia, and Europe, there are such groups meeting in someone's living room. Now are they starting to become recognized. Gabor Gombos, whom you now know, is president of the Mental Health Interest Forum in Hungary, known by the Hungarian acronym PEF. The government of Hungary recognizes PEF's work. This is an organization run by psychiatric consumers. The organization provides this otherwise marginalized group of people the opportunity to comment on proposed mental health laws and policies. When abuses take place, the organization speaks out and holds the government accountable. They have now received considerable press attention in Hungary for their work.

Just last year, Gabor Gombos was picked as one of the top fifty human rights activists in the world. This was part of a program pulled together by Kerry Kennedy Cuomo to honor people who put their lives at stake to further the cause of human rights. Just a year ago, they held an awards ceremony at the John F. Kennedy Center in Washington, D.C. Awards went to such leaders as Vaclav Havel and the Dalai Lama, some of the most courageous and accomplished proponents of human rights in the world. President Clinton and other political leaders came to greet and honor them. You should know that Gabor Gombos was among those fifty human rights leaders who had put their life on the line for their cause. He is among the fifty world human rights leaders who have helped transformed the way the public understand the meaning of what we refer to as human rights.

The world is starting to see that mental disability rights are indeed part of the international human rights spectrum. We are not talking about a special kind of right. We are talking about human rights just like other human rights. We are talking about special people, however, who have been ignored too long

by the human rights movement. Gabor Gombos is leading the way to showing that these people should not and cannot be left out much longer.

Ten years ago when I was still in law school at Georgetown, my background had been in the work of the domestic U.S. civil rights field. I was a paralegal at a civil rights organization then called the Mental Health Law Project. It is now called the Judge David L. Bazelon Center for Mental Health Law. I heard Michael Perlin speak at a conference way back then. I got my education about the meaning of civil rights working at the Mental Health Law Project. My job was to take calls from the public and to refer them to attorneys or other advocacy resources. In the process, I learned about the day-to-day humiliations, deprivations, and abuses to which U.S. citizens with disabilities are subject with mind-numbing frequency. When I went to law school, however, I decided to go into international human rights. I wanted to find out what could be done to fight against the most serious human rights abuses the world over. When I went to law school, I was shocked to find how little the international human rights community knew about the concerns of people with mental disabilities. I began to study the application of international human rights law to the situation of people with mental disabilities.

The law review article distributed in your conference packet is a piece that I first drafted for a seminar course in law school. It has turned out to lay much of the intellectual groundwork of my career as a human rights activists. I encourage all law students to take seriously the writing they do in law school because it may come back to haunt them. I've lived with this article for the last ten years — mostly in a good way.

I began my research for the article by examining the human rights studies of non-governmental organizations such as Human Rights Watch and Amnesty International. I also looked at the U.S. Department of State's *Country Reports on Human Rights Practices*. What I found is shocking: those human rights organizations and human rights reports criticized governments when political dissidents were put in psychiatric facilities, but they did not speak out about the abuses against other people who may or may not have mental disabilities. The classic case of such reporting took place in the Soviet Union. When political dissidents were put in psychiatric facilities, such as the Pavlov Psychiatric facility in Kiev, human rights organizations would report that they visited a one-thousand-bed facility and they found human rights abuses against three people in the institution who had been placed there because they were political dissidents.

As they described these abuses, it sounded as if the worst thing that could be done to a person was to be forced to associate with those mentally ill people who were in the beds next to them. They described how the beds were so close together that the dissidents could not even stand up. They were forced to take horrendous psychotropic medications. But what about the rights of the other thousand people in the facility? What about the fact that they could also not get out of bed because of the overcrowding? What about the fact that they

were forced to take those horrendous psychotropic medications? What about their rights?

It never dawned on the human rights organizations to hold governments accountable for the violations of the rights of people with mental disabilities. Ten years later, there has been tremendous progress. The very fact that Krasimir Kanev would come to speak here today is a sign that things have changed. He is a member of the Helsinki Committee of Bulgaria, one of the organizations that spoke out against political abuses ten years ago. Now his organization is one of the mainstream human rights organizations in Bulgaria that is speaking out about people with mental disabilities. When we asked Krassimir to visit (actually he originally invited us to come to Bulgaria), he also invited someone from Amnesty International to join us on our investigation. After years of ignoring this issue, Amnesty now accepted the invitation. Amnesty, I must say, once had a horrendous record with regard to people with mental disabilities. We heard earlier in this conference about the use of so-called "unmodified ECT." That is ECT without muscle relaxants or anesthesia. There is actually an Amnesty International report from just over ten years ago that looked at that practice in Romania, and said that it was not a human rights violation because the intent of the medical practitioner was to help the patient, even though the practice of unmodified ECT causes tremendous pain and possibly life-threatening dangers. According to Amnesty's way of thinking, this was not a human rights violation appropriate for international recrimination. It was merely a question of "medical ethics." Somehow, when it is a question of medical ethics, you can leave it to the doctors and police to fight it out amongst each other about how best to treat their patients.

The fact that a major mainstream human rights organization discovered such barbaric practices over ten years ago, but now accepted our invitation to visit these institutions as part of a human rights investigation is great progress. When they came on this investigation, and when the researcher from Amnesty International saw people detained in horrendous facilities — including women detained in a cage — he was shocked.

Now, after years and years of dragging its heels, Amnesty International came out with an Urgent Action Campaign. This is an historic event. This is a worldwide statement that the abuse of people with mental disabilities in a psychiatric facility — even in the name of treatment — is an international human rights violation. My understanding is that, as a result of this campaign, the cage has been closed down. This is an enormous breakthrough for an organization like Amnesty International and for the international human rights community as a whole.

In Hungary five years ago when Mental Disability Rights International first published our report *Human Rights and Mental Health: Hungary*, we documented people in cages. We sent our report to Amnesty International and Human Rights Watch and the U.S. Department of State. They all ignored it. Just two years ago, Harold Koh, the Assistant Secretary of State for Democ-

racy, Human Rights, and Labor under President Clinton — a person with a disability himself — saw our report and took an interest in the matter. We discussed our findings from Hungary with Secretary Koh and his staff. As a result, the U.S. Department of State put one line about the use of cages in the United States' official Country Report on Human Rights Practices. After five years of banging on the door in Hungary, after five years of disseminating a fifty-page and extensively documented report about abuses in Hungary's mental health facilities, it took just two days for a response. Two days after the publication of the U.S. State Department report, officials from the Ministry of Welfare called Gabor Gombos and asked him for advice about what to do about the cages. They signaled their willingness to consider the abolishment of the use of cages if we could come up with an alternative. They asked Gabor to send a message to MDRI for our suggestions about practices for controlling unruly patients and legal regulations that had proved successful in other countries. More significantly, perhaps, they also asked Gabor and PEF what they would suggest. I cannot imagine the authorities turning to the psychiatric survivors for their opinion on the cages just five years earlier.

This experience shows that when the mainstream human rights community speaks up, people will listen. It also has a ripple effect. It makes clear to the public, to the medical community, and to government authorities that improper medical or psychiatric practice is more than an ethical conundrum. It is a violation of human rights that requires changes in practice. It is our responsibility in the international human rights community to speak out about human right abuses in mental health systems as we would speak out about the detention or torture or killing of political dissidents. We must say, "No more, never again. We will not tolerate abuses of this kind."

There is so much more that needs to be done. Activists around the world continue to be ignored. In collaboration with Gabor Gombos and activists from Ireland, MDRI recently sent a team into Kosovo. Despite the fact that the international community moved into Kosovo to challenge human rights violations, we found horrific human rights abuses in psychiatric facilities in Kosovo. Women were being raped in front of the staff of internationally-funded humanitarian relief organizations. A Spanish psychiatrist said he saw a woman being raped in front of them. When he asked why staff did not try to stop it, he was told that the practice was considered "normal" in the psychiatric facility.

We brought the findings of our investigation to the various organizations that the United Nations had supported, the civil society and human rights organizations. At the Prishtina office of the Organization for Security and Cooperation in Europe ("OSCE"), officials expressed shock at the stories we told them about abuses in Kosovo's psychiatric facilities. Yet they had no official means of action. There were no specialized programs set up to deal with this. It simply never dawned on people ahead of time that they would have to fight abuses of this kind. They agreed that somehow this issue should fit into the

work of the civil society and human rights programs that have been so well funded in Kosovo, and yet the issue never made its way to the top of the agenda of any of these programs. It was just not a priority. The people with mental disabilities in the institutions had no interest groups in society ready to push their issues to the top. Based on these frustrating experiences, MDRI decided to issue a public report criticizing the United Nations for its failure to protect the rights of people in institutions in Kosovo.²

Much more needs to be done. The international legal brain work is there. The core protections that exist under international human rights law do theoretically protect people with mental disabilities. The language of the prohibition against discrimination in the Universal Declaration of Human Rights and the International Covenant of Civil and Political Rights never mentions people with disabilities. However, these provisions have been recently interpreted to include people with disabilities. The Covenant of Civil and Political Rights, drafted shortly after the Second World War, also says that there shall be no inhumane or degrading treatment or torture. In one of the most specific lines in the Covenant it states that there shall be no experimentation on human subjects without their "voluntary consent." The drafters had the immediate experience of the holocaust in mind in which doctors experimented on patients in the concentration camps. The very idea that medical professionals had to be held accountable for what they did to patients was thus linked to the definition of international human rights movements since their inception.

This is why it is so deeply disturbing when international human rights activists just ten years ago — and today — would defer so completely to medical judgment. If the doctor is trying to help, the thinking goes, it must be okay. That is no longer acceptable. Yet, despite the fact that the international human rights protection exists, the international human rights community has not been listening for too long. This is the system as we now have it and it is broken. The international human rights system is not protecting people with mental disabilities. We must do more.

We heard from Krassimir Kanev how international standards are essentially non-binding interpretations of treaties and how the standards themselves are inconsistent. Even the standards themselves use outdated terminology that are offensive to many of the advocates. Look, for example, at the UN Declaration on the Rights of Mentally Retarded Persons.

There is a growing movement of people with mental disabilities who find that term "mental retardation" derogatory. Yet the best available statement of their rights are in this international instrument. The United Nations General Assembly's "Principles for the Protection of Persons with Mental Illness" also

2. MDRI has since published a report on the findings of that mission. *Not on the Agenda: Human Rights Abuse Against People with Mental Disabilities in Kosovo* (Aug. 8, 2002). This report can be found on MDRI's website at www.MDRI.org. The report received extensive worldwide press attention. See, e.g., *Forgotten by the United Nations*, editorial in THE WASHINGTON POST (Aug. 8, 2002).

known as the MI Principles, have some of the same flaws. Instead of referring to the rights of “people” with mental illness or individuals with psychiatric disabilities, this instrument refers to “patients.”

What about people who question the medical model which says we are human beings and we have rights. Are peoples’ rights determined because medical authorities determine that they have “mental illness?” Do they have rights because they are voluntary or involuntary “patients?” We have to look to the day when human rights are protected because people are people, not patients. The MI Principles, although they are valuable, still represent human rights in a medicalized framework. So when I said a few minutes ago that what you have to be careful what you write in law school — because it may come back to haunt you — ten years ago I wrote an article, about the importance of the MI Principles. I stand by my legal analysis — the MI Principles are the best available interpretation of international covenants and they are an important interpretation of international covenant. Whether we like it or not, they do represent international law and we should make the best of it in some contexts, and ignore them in others. I wrote ten years ago that the MI Principles could be used a “model laws” for countries that had no mental health law. I have now learned that, even if they are better than existing laws, they should not be used as a model.

Indeed, the fact that the organized movement of people with psychiatric disabilities has rejected them is highly significant because ultimately the seeking the recognition of new rights is a political as well as a legal process. If a particular instrument lacks political support because people feel insulted by legal standards intended to protect them we will never get political support for those rights. International instruments are often used as an educational tool. That value is undermined where the instrument helps perpetuate stereotypes of people with mental disabilities. As a legal matter, the MI Principles can be used to undermine and disempower people in certain contexts. We now have an opportunity to get beyond that. There is a tremendous new opportunity for advancing international human rights because last December the General Assembly approved a resolution to convene an Ad Hoc Committee to begin drafting a new International Convention on the Rights of People with Disabilities. This process gives us a second chance to draft standards that are empowering and that serve as a model of what we would like to see as part of international law.

It is ironic that this resolution in the General Assembly was sponsored by the government of Mexico. Mental Disability Rights International documented very serious abuses in Mexican psychiatric facilities just two years ago. Our work was written up in the New York Times, and the government of Mexico was extremely embarrassed about the conditions in its institutions. We brought our findings to the Inter-American Commission on Human Rights of the OAS. The OAS report on Mexico raised concerns about Mexico’s treatment practices in psychiatric institutions. The government of Mexico has now

said they will support a new convention on the rights of people with disabilities and they will work through the U.N. to get support for this effort.

This is a tremendous new opportunity to transform international human rights law. It opens up a new world of possibilities. On the one hand, there are important ways in which international law can be improved. But it will be a challenge to do so. International conventions are ultimately consensus documents, unlike aspirational human rights declarations adopted through the General Assembly. For a convention to be legally binding, it must be ratified by national governments. For a convention to enter into force, you have to get a good deal of agreement from different countries. No convention is as strong as you want it to be. We may have to strategize how we can use the more general language of anti-discrimination to obtain our goals. If the convention allows us to "lock-in" some principles of anti-discrimination as enforceable international law, this will allow us to put off the question of its ultimate content to a future date. We may be able to move consensus along over time through a variety of legal and political advocacy strategies. If we adopt this long-term approach, we can start to plan our activities strategically. We train activists, we work to establish model laws in different countries, and we document effective practices. We work hard to educate the public by disseminating information about these positive practices, and about continuing abuses. We demonstrate that in every country of the world, people with mental and physical disabilities are subject to discrimination, kept out of public spaces, and abused behind the closed doors of institutions. By working to gain support for the convention, we can galvanize public attention to these issues. In the long-term, this process of public education process may be as important as the convention itself.

If we are successful in gaining support for a new convention, the procedural mechanisms we establish for the enforcement of that convention become critical. As part of the convention, we would hope to create a new oversight body. Governments that ratify the convention could be required to report regularly on the steps they take to implement the convention. The oversight body could review those reports and issue public comments on them. This would ensure constant attention to disability rights issues. It will be a way to hold governments accountable. The oversight body could issue "general comments" on the meaning of the convention that would advance the interpretation of the new international law.

The United States National Council on Disability ("NCD"), which is the highest U.S. federal advisory body on disability, issued a white paper that will be published in the next couple of months arguing for why a new international disability rights convention. I strongly suggest that you contact the NCD to obtain copies of that white paper. It will be on the NCD website. I am confident that we can get support for a convention over time. But our ability to do so will depend on the development of a new political movement with a very big task of both domestic and international organizing. Disability rights and

mental disability rights organizations are going to have to take a stand on international human rights. Human rights organizations are going to have to take a stand on disability rights. We have to establish new alliances bring out best allies on board first. Only then can we get governments to back up the convention.

Unfortunately, we are in a particularly difficult situation here in the United States. The United States government is one of the most conservative governments in the world when it comes to international conventions. It is very hard to get United States government support for any international conventions. Yet, ironically, we have the strongest disability rights movement in the world. We have the best organization. We have got very good legislative models and legal precedent. We have invaluable experience on which to draw.

In Western Europe, disability activists look to the United States with great admiration. Even though much of Western Europe has better social service models than the United States, there are very few countries with better laws. The Americans with Disability Act is an international inspiration. Now, as long as the United States government does not stand in the way of a new convention, activists in the United States have an opportunity to build on our experience and shape the new legal regime.

Now is our opportunity to be integrated in the world disability rights community and to participate in furthering international law. But we can only do so if we take a stand on these rights. I encourage all of you to get involved as lawyers and as activists. If you are a part of organizations that can weigh-in with a significant US constituency, you have your work cut out for you. This is true even if your networks are not international and you have never done international work before. Organizing to gain support for a convention is your chance to make a difference for people with mental or physical disabilities around the world.

Thank you.

V. BRIDGING THE GAP: AMERICAN AND OTHER PERSPECTIVES

MR. DUBINSKY*: I am Paul Dubinsky and I am on the faculty here. I teach international law and international human rights in general. "Bridging the Gap American and Other Perspectives," is the name of our last panel.

I admire Professor Perlin enormously. There is a movement against torture and interrogation. Once you get to the point where you are ready to put pen to paper and are ready to draft laws and mechanisms, then it becomes interesting and complicated. You quickly find that there is one set of rights that potentially conflict with another set of rights, and that maybe the institu-

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