OFFICE OF THE COMMISSIONER
FOR HUMAN RIGHTS

BUREAU DU COMMISSAIRE
AUX DROITS DE L´HOMME

COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

CommDH(2003)3
bil.

SEMINAR ON / *SEMINAIRE SUR*

THE PROTECTION AND PROMOTION OF THE HUMAN RIGHTS OF PERSONS WITH MENTAL DISABILITIES

LA PROTECTION ET LA PROMOTION DES DROITS DE L'HOMME DES PERSONNES AYANT DES PROBLEMES DE SANTE MENTALE

Organized by / *organisé par*

THE COMMISSIONER FOR HUMAN RIGHTS /
LE COMMISSAIRE AUX DROITS DE L'HOMME

and hosted by / *et accueilli par*

THE WHO REGIONAL OFFICE FOR EUROPE /
LE BUREAU REGIONAL DE L'OMS POUR L'EUROPE

proceedings / actes

Copenhagen, Denmark, 5-7 February 2003

F – 67075 Strasbourg Cedex, Fax : + 33 90 21 50 53, http://www.commissioner.coe.int, e-mail : commissioner.human rights@coe.int

TABLE OF CONTENTS / SOMMAIRE

Pages

OPENING SESSION / SESSION D'OUVERTURE ……………………………….. 5

Speeches / Discours

Mr Lars Loekke RASMUSSEN,
Danish Minister for the Interior and Health ………………………………………. 7

Mr Paulo COEHLO,
Author, Brazil ……………………………………………………………………………. 9

Mr Andres LEHMETS,
First Vice-President of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment of Punishment (CPT) …………………. 13

I. FIRST SESSION / PREMIERE SESSION …………………………………... 17

Mental health and human rights / Santé mentale et droits de l'homme

Mental health and human rights
Mr Stephen P. MARKS, *François-Xavier Bagnoud Professor of Health and Human Rights, Harvard School of Public Health (United States)* …………………….. 19

Compulsion, confidentiality and consent – three current dilemmas in human rights and mental disorders
Lord ALDERDICE, *Speaker of the Northern Ireland Assembly and Consultant Psychiatrist* ……………………………………………………………….... 33

II. SECOND SESSION / DEUXIEME SESSION ………………………………... 37

Restrictions on liberty : procedures and criteria for involuntary and non-voluntary placement and treatment / Restrictions à la liberté : procédures et critères pour le placement et le traitement involontaires et non-volontaires

Involuntary detention and treatment of persons of « unsound mind »
Mrs Orsolya SZEKELY, *Lawyer at the European Court of Human Rights*……………….... 39

III. THIRD SESSION / TROISIEME SESSION …………………………………….. 45

Integrity and dignity / Intégrité et dignité

Safeguarding people with mental health problems against abuse
Mrs Hilary BROWN, *Professor, Canterbury Christ Church University*…………………… 47

Pages

IV. FOURTH SESSION / QUATRIEME SESSION …………………………………….. **51**

Equality, non-discrimination and social justice : employment, education, health care, social security / Egalité, non-discrimination et justice sociale : emploi, éducation, soins médicaux, sécurité sociale

Protecting the rights of people with mental disabilities: the European Convention on Human Rights
Mr Oliver LEWIS, *Legal Director,*
Mentality Disability Advodacy Centre, Budapest ……………………………………………… **53**

V. FIFTH SESSION / CINQUIEME SESSION ………………………………………... **73**

Implementation of access to the rights, responsibility, monitoring and lobbying : the role of governments, NGOs and civil society / Mise en application de l'accès aux droits, la responsabilité, le contrôle et le lobbying: le rôle des gouvernements, les ONG et la société civile

Dr Athanassios CONSTANTOPOULOS, *Director, Mental Health Centre, Greece* …………………. **75**

CLOSING SESSION / SESSION DE CLOTURE ………………………………………... **83**

Closing speech by / Discours de clôture par :

Alexandre JOLLIEN
Philosopher, Switzerland ……………………………………………………………………. **85**

APPENDICES / ANNEXES... ………………………………….……………………... **87**

A. Conclusions ……………………………………………………………………………..... **89**

B. Programme ………………………………………………………………………………. **97**

C. List of participants / Liste des participants ………………………………………………. **103**

OPENING SESSION

Speeches

SESSION D’OUVERTURE

Discours

Speech by Mr I. VALSBORG,
on behalf of Mr L. RASMUSSEN,
Danish Minister for the Interior and Health

Exellencies,

The Minister has asked me to extend his gratitude to the Commissioner for Human Rights of the Council of Europe Mr Gil-Robles and the World Health Organization for the invitation to participate in the opening of this most important seminar.

On behalf of the Minister it is both a privilege and a pleasure to be able to welcome you all to Copenhagen.

The topic of the seminar “ The protection and the promotion of the human rights of persons with mental disabilities” is most certainly an important issue. An issue that is ever present – and should be – in the continuous debate about the conditions we offer our mentally disabled fellow countrymen. The guiding principle of the Danish health care system towards people with mental disabilities is to facilitate a life as close to “normal” as possible. A life where the individual is able to live a valuable and meaningful life as an integrated part of society. A life of inclusion – not exclusion. Inclusion necessitates understanding, empathy and openness from the surrounding society. Therefore it is very important to popularise the common knowledge of mental disabilities and their effects so as to limit taboos and marginalisation of these groups of people. Why? Because exclusion and thereby loneliness and isolation are the worst and strongest allies of mental disabilities. And when it comes to social acceptance – it is my general impression that one is still far better off with a broken arm, than if you are hearing voices In other words – it is easier to relate to a broken arm than for example inexplicable voices. But it takes time to change the general attitude towards persons with mental disabilities in the public, though I am sure that the continuous information in the long run can facilitate the required changes. And we are optimistic – because it is our impression – that we are making progress though we still have a lot of work ahead of us.

The Danish Government gives high priority to the treatment and care of the mentally disabled in our society. And it is the general impression that the political priority as such contributes to the necessary move from exclusion towards inclusion – of this group of people – in everyday life. But what about the years to come – what are the Danish Governments future focus points in this area? Well, one important focus point is the need for ever more coherent courses of treatment and care to persons with mental disabilities. Here the Danish Government finds it extremely important that the point of departure is the need for treatment and care of the individual. It is the principal duty for the health care system to fulfil these needs; It should never be the other way around. It is the Danish Government’s belief that as far as possible the mentally disabled should be involved in the choice of the treatment. Therefore it is also important that we strive to offer a variety of treatments, so as to give the patient a possible choice of treatment. Another important focus point for the Danish Government in this area is the continuous securing of improvement in the quality of the treatments offered to persons with mental disabilities. Implementation of “best practice” is something we should be able to take for granted. The Danish National Board of Health have recently presented a catalogue with a number of initiatives that the government is convinced will further heighten the overall standards of treatment in the years to come.

Finally, I will stress the importance of the continuing securing of the basic rights of persons with mental disabilities. Securing the basic rights of persons with mental disabilities in relation to treatment and perhaps especially involuntary treatment is much like walking on a razor's edge. On one hand we have to make sure that the basic rights of the person are not violated. On the other hand we have to make sure that our effort to secure the basic rights of the individual does not result in failing our duty to provide proper treatment and care for the person in need.

I hope this brief overview of the Danish Government's considerations in relation to the efforts of the Danish health care system – towards persons with mental disabilities – can be of some inspiration when you during the next two days are going to discuss the protection and promotion of the human rights of this very same group of people.

On behalf of the Minister I wish everybody a fruitful seminar and a pleasant stay here in Copenhagen.

Thank you for your attention.

Speech by Mr Paulo COEHLO,
Author, Brazil

'I entered a tiled cubicle. There was a bed covered with a rubber sheet and beside the bed some sort of apparatus with a handle."So you're going to give me electric shock treatment," I said to Dr Benjamim Gaspar Gomes. "Don't worry. It's far more traumatic watching someone being treated than actually having the treatment yourself. It doesn't hurt at all."

I lay down and the male nurse put a kind of tube in my mouth so that my tongue wouldn't roll back. Then, on either temple, he placed two electrodes, rather like the earpieces of a telephone. I was looking up at the peeling paint on the ceiling when I heard the handle being turned. The next moment, a curtain seemed to fall over my eyes; my vision quickly reduced down to a single point, and then everything went dark. The doctor was right; it didn't hurt at all.'

The scene I have just described is not taken from my latest book. It comes from the diary I wrote during my second stay in a mental hospital. That was in 1966, the beginning of the blackest period of Brazil's military dictatorship (1964-1989), and, as if by some natural reflex of the social mechanism, that external repression was gradually becoming. So much so that good middle-class families found it simply unacceptable that their children or grandchildren should want to be 'artists'. In Brazil at the time, the word 'artist' was synonymous with homosexual, communist, drug addict and layabout.

When I was 18, I believed that my world and that of my parents could coexist peacefully. I did my best to get good marks at the Jesuit school where I was studying, I worked every afternoon, but at night, I wanted to live out my dream of being an artist. Unfortunately, my parents did not share my belief in the peaceful coexistence of two such diametrically opposed worlds. One night, I came home drunk, and the following morning, I was woken by two burly male nurses. 'You're coming with us,' one of them said. My mother was crying, and my father was doing his best to hide any feelings he might have. 'It's for your own good,' he said. 'We're just going to have some tests done.'

And thus began my journey through various psychiatric hospitals. I was admitted, I was given all kinds of different treatments, and I ran away at the first opportunity, travelling around for as long as I could bear it, then going back to my parents' house. We enjoyed a kind of honeymoon period, but, after a while, I again started to get into what my family called 'bad company', and the nurses reappeared.

The situation I found myself in was so strange, so extreme, that it brought with it something unprecedented: total freedom. All my family's efforts to make me the same as everyone else had exactly the opposite result: I was now completely different from all the other young men of my own age.

One night, I considered my future. One option was to become a writer; the other, which seemed more viable, was to go properly mad. I would be supported by the State, I would never have to work or take on any responsibility. I would, of course, have to spend a great deal of time in mental institutions, but I knew from my own experience that patients there do not behave like the mad people you see in Hollywood films. Apart from a few pathological cases of catatonia or schizophrenia, all the other patients were perfectly capable of talking about life and had their own highly original ideas on the subject. Every now and then, they would suffer panic attacks, bouts of depression or aggression, but these did not last.

The greatest risk I ran in hospital was not of losing all hope of ever becoming President of the Republic, nor of feeling marginalised or unfairly treated by my family - because in my heart I knew that having me admitted to hospital was a desperate act of love and over-protectiveness on their part. The greatest risk I ran was of coming to think of that situation as normal.

When I came out of hospital for the third time - after the usual cycle of escaping from hospital/travelling around/going back home/enjoying a honeymoon period with my family/getting into bad company again/being readmitted into hospital - I was nearly twenty and had become accustomed to that rhythm of events. This time, however, something had changed.

Although I again got into 'bad company', my parents were growing reluctant to have me readmitted to a mental hospital. Unbeknown to me, they were by then convinced that I was a hopeless case, and preferred to keep me with them and to support me for the rest of my life.

My behaviour went from bad to worse, I became more aggressive, but still there was no mention of hospital. I experienced a period of great joy as I tried to exercise my so-called freedom, in order, finally, to live the 'artist's life'. I left the new job my parents had found for me, I stopped studying, and I dedicated myself exclusively to the theatre and to frequenting the bars favoured by intellectuals. For one long year, I did exactly as I pleased; but then the theatre group was broken up by the political police, the bars became infiltrated by spies, my stories were rejected by every publisher I sent them to, and none of the girls I knew wanted to go out with me - because I was a young man without a future, with no real career, and who had never even been to university.

So, one day, I decided to trash my bedroom. It was a way of saying, without words: 'You see, I can't live in the real world. I can't get a job, I can't realise my dream. I think you're absolutely right: I am mad, and I want to go back to the mental hospital!'

Fate can be so ironic! When I had finished wrecking my room, I was relieved to see that my parents were phoning the psychiatric hospital. However, the doctor who usually dealt with me was on holiday. The nurses arrived with a junior doctor in tow. He saw me sitting there surrounded by torn-up books, broken records, ripped curtains, and asked my family and the nurses to leave the room. 'What's going on?' he asked. I didn't reply. A madman should always behave like someone not of this world. 'Stop playing around,' he said. 'I've been reading your case history. You're not mad at all, and I won't admit you to the hospital.'

He left the room, wrote a prescription for some tranquillisers and (so I found out later) told my parents that I was suffering from 'admission syndrome'. Normal people who, at some point, find themselves in an abnormal situation - such as depression, panic, etc. - occasionally use illness as an alternative to life. That is, they choose to be ill, because being 'normal' is too much like hard work. My parents listened to his advice and never again had me admitted into a mental institution.

From then on, I could no longer seek comfort in madness. I had to lick my wounds alone, I had to lose some battles and win others, I often had to abandon my impossible dream and work in offices instead, until, one day, I gave it all up for the nth time and I went on a pilgrimage to Santiago de Compostela. There I realised that I could not keep refusing to face up to my fate of 'being an artist', which, in my case, meant being a writer. So, at 38, I decided to write my first book and to risk entering into a battle which I had always subconsciously feared: the battle for a dream.

I found a publisher and that first book (The Pilgrimage - about my experience on the Road to Santiago) led me to The Alchemist, which led me to others, which led to translations, which led to lectures and conferences all over the world. Although I had kept postponing my dream, I realised that I could do so no longer, and that the Universe always favours those who fight for what they want.

In 1997, after an exhausting promotional tour across three continents, I began to notice a very odd phenomenon: what I had wanted on that day when I trashed my bedroom seemed to be something a lot of other people wanted too. People preferred to live in a huge asylum, religiously following rules written by who knows who, rather than fighting for the right to be different. On a flight to Tokyo, I read the following in a newspaper:

According to Statistics Canada: 40% of people between 15 and 34, 33% of people between 35 and 54, and 20% of people between 55 and 64 have already had some kind of mental illness. It is thought that one in every five individuals suffers from some form of psychiatric disorder.

I thought: Canada has never had a military dictatorship, it's considered to have the best quality of life in the world, why then are there so many mad people there? Why aren't they in mental hospitals?

That question led me on to another: what exactly is madness? I found the answers to both those questions. First, people aren't in mental institutions because they continue to be socially productive. If you are capable of getting in to work at 9.00 a.m. and staying until 5.00 p.m., then society does not consider you incapacitated. It doesn't matter if, from 5.01 p.m. until 8.59 a.m. you sit in a catatonic state in front of the television, indulge in the most perverted sexual fantasies on the Internet, stare at the wall, blaming the world for everything and feeling generally put upon, feel afraid to go out into the street, are obsessed with cleanliness or a lack of cleanliness, suffer from bouts of depression and compulsive crying. As long as you can turn up for work and do your bit for society, you don't represent a threat. You're only a threat when the cup finally overflows and you go out into the street with a machine gun in your hand, like a character in a child's cartoon, and kill fifteen children in order to alert the world to the pernicious effects of Tom and Jerry. Until you do that, you are deemed to be normal.

And madness? Madness is the inability to communicate.

Between normality and madness, which are basically the same thing, there exists an intermediary stage: it is called 'being different'. And people were becoming more and more afraid of 'being different'. In Japan, after giving much thought to the statistical information I had just read, I decided to write a book based on my own experiences. I wrote Veronika Decides to Die, in the third person and using my feminine ego, because I knew that the important subject to be addressed was not what I personally had experienced in mental institutions, but, rather, the risks we run by being different and yet our horror of being the same.

When I had finished, I went and talked to my father. Once the difficult time of adolescence and early youth was over, my parents never forgave themselves for what they did to me. I always told them that it really hadn't been that bad and that prison (for I was imprisoned three times for political reasons) had left far deeper scars, but my parents refused to believe me and spent the rest of their lives blaming themselves.

'I've written a book about a mental institution,' I said to my 85-year-old father. 'It's a fictional work, but there are a couple of pages where I speak as myself. It means going public about the time I spent in mental hospitals.'
My father looked me in the eye and said:
'Are you sure it won't harm you in any way?'
'Yes, I'm sure.'
'Then go ahead. I'm tired of secrets.'

Veronika Decides to Die came out in Brazil in August 1998. By September, I had received more than 1,200 e-mails and letters relating similar experiences. In October, some of the themes touched on in the book - depression, panic attacks, suicide - were discussed in a seminar that had national repercussions. On 22 January 1999, Senator Eduardo Suplicy, read out passages from my book to the other senators, and managed to get approval for a law which they had been trying to get through the Brazilian Congress for the last ten years, a law forbidding arbitrary admissions into mental institutions.

Speech by Dr Andres LEHTMETS,

First Vice-President of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment of Punishment (CPT)

Dear guests,

I was asked by the organizers to address you on behalf of the CPT, a committee in protection of the human rights of persons deprived of their liberty. The committee has a long name: in full it is called the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment of Punishment (CPT). The word “torture” in the name of our committee always attracts attention; we are however not only after the most cruel and violent ill-treatment episodes; a lot of our work is actually related to evaluating the conditions and treatment of persons deprived of their liberty by the public authority.

The focus of our work is not only on prisoners or persons detained in police stations. Over the more than 10 years of its existence the committee has on numerous occasions visited also psychiatric hospitals, nursing-homes for mentally ill, children’s homes, but also prison mental hospitals in order to evaluate the conditions and look after the rights of the persons deprived of their liberty by the public authority.

The committee is operating on the basis of a convention – the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment of Punishment that was passed in 1987 and that became operational in 1999. For the time being 44 countries have signed the convention and opened their institutions to the committee for visits. I should emphasise from the very beginning, that the work of the committee is based on 2 basic principles – confidentiality and cooperation. The reports of the committee remain confidential and are only opened to the public if the state in question so decides. I should however emphasise, that nearly all the member states have decided to publish the reports of the committee; strengthening this way the cooperation side laid down in the convention. This fact makes the CPT an important tool for the prevention of ill-treatment and degrading treatment – as well as acts amounting to torture – of persons deprived of their liberty.

The focus of this conference is on the protection and promotion of human rights of persons with mental disabilities. For our committee, these persons are especially vulnerable for two reasons. First of all, in many countries the many of these people spend their days in big institutions, often committed there without their consent. Secondly, these people are an especially vulnerable category in prisons and other places of deprivation of liberty - and for that reason their rights have to be looked after with special care.

The CPT visits palaces of detention in the member states – on regular basis, but also on ad hoc basis – on a very short notice only. This gives us the opportunity to have access to the conditions as they are – without the unnecessary extra polish and play so common for visits notifies before. According to the mandate we have the right to speak to persons in private – as well as acquire all the necessary information needed for us to carry out our task. Let me briefly focus on some aspects of our visits and some principles that we consider important and necessary in our work.

In view of its mandate, the CPT's first priority when visiting a psychiatric establishment or an institution for mentally disabled persons must be to ascertain whether there are any indications of the deliberate ill-treatment of patients. Such indications are seldom found. Nevertheless, the CPT's own on-site observations and reports received from other sources indicate that the deliberate ill-treatment of patients or residents does occur from time to time.

In some countries, we have encountered the practice of using certain patients, or inmates from neighboring prison establishments, as auxiliary staff in psychiatric facilities. The Committee has serious misgivings about this approach. It is also essential that appropriate procedures be in place in order to protect certain psychiatric patients from other patients who might cause them harm. Further, specific arrangements should be made for particularly vulnerable patients; for example, mentally handicapped and/or mentally disturbed adolescents should not be accommodated together with adult patients.

Similarly, rules and practices capable of generating a climate of tension between staff and patients should be revised accordingly. The imposition of fines on staff in the event of an escape by a patient is precisely the kind of measure which can have a negative effect on the ethos within a psychiatric establishment.

The CPT closely examines patients' living conditions and treatment; inadequacies in these areas can rapidly lead to situations falling within the scope of the term "inhuman and degrading treatment". The aim should be to offer material conditions which are conducive to the treatment and welfare of patients; in psychiatric terms, a positive therapeutic environment. Further, adequate treatment and care, both psychiatric and somatic, must be provided to patients; having regard to the principle of the equivalence of care, the medical treatment and nursing care received by persons who are placed involuntarily in a mental institution should be comparable to that enjoyed by voluntary psychiatric patients or residents.

I would also wishes to make clear our support for the trend observed in several countries towards the closure of large-capacity dormitories in psychiatric establishments; such facilities are scarcely compatible with humane psychiatry. Provision of accommodation structures based on small groups is a crucial factor in preserving/restoring patients' dignity, and also a key element of any policy for the psychological and social rehabilitation of patients.

Psychiatric treatment should be based on an individualised approach, which implies the drawing up of a treatment plan for each patient. It should involve a wide range of rehabilitative and therapeutic activities, including access to occupational therapy, group therapy, individual psychotherapy, art, drama, music and sports. The CPT all too often finds that these fundamental components of effective psycho-social rehabilitative treatment are underdeveloped or even totally lacking, and that the treatment provided to patients consists essentially of pharmacotherapy. This situation can be the result of the absence of suitably qualified staff and appropriate facilities or of a lingering philosophy based on the custody of patients.

Patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of a person to a mental institution on an involuntary basis should not be construed as authorizing treatment without his consent. It follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances.

In some countries, the CPT has been particularly struck by the small number of qualified psychiatric nurses among the nursing staff in psychiatric establishments, and by the shortage of personnel qualified to conduct social therapy activities (in particular, occupational therapists). The development of specialized psychiatric nursing training and a greater emphasis on social therapy would have a considerable impact upon the quality of care. In particular, they would lead to the emergence of a therapeutic milieu less centered on drug-based and physical treatments.

In any psychiatric establishment, the restraint of agitated and/or violent patients may on occasion be necessary. This is an area of particular concern to the CPT, given the potential for abuse and ill-treatment. The restraint of patients should be the subject of a clearly-defined policy. That policy should make clear that initial attempts to restrain agitated or violent patients should, as far as possible, be non-physical (e.g. verbal instruction) and that where physical restraint is necessary, it should in principle be limited to manual control. If, exceptionally, recourse is had to instruments of physical restraint, they should be removed at the earliest opportunity; they should never be applied, or their application prolonged, as a punishment. There is a clear trend in favour of avoiding seclusion of patients, and the CPT is pleased to note that it is being phased out in many countries. Seclusion should never be used as a punishment.

On account of their vulnerability, the mentally ill and mentally handicapped warrant much attention in order to prevent any form of conduct - or avoid any omission - contrary to their well-being. It follows that involuntary placement in a psychiatric establishment should always be surrounded by appropriate safeguards. The procedure by which involuntary placement is decided should offer guarantees of independence and impartiality as well as of objective medical expertise.

As regards, more particularly, involuntary placement of a civil nature, in many countries the decision regarding placement must be taken by a judicial authority (or confirmed by such an authority within a short time-limit), in the light of psychiatric opinions. However, the automatic involvement of a judicial authority in the initial decision on placement is not foreseen in all countries. In any event, a person who is involuntarily placed in a psychiatric establishment by a non-judicial authority must have the right to bring proceedings by which the lawfulness of his detention shall be decided speedily by a court.

Further, as in any place of deprivation of liberty, an effective complaints procedure is a basic safeguard against ill-treatment in psychiatric establishments. Specific arrangements should exist enabling patients to lodge formal complaints with a clearly designated body, and to communicate on a confidential basis with an appropriate authority outside the establishment.

The CPT also attaches considerable importance to psychiatric establishments being visited on a regular basis by an independent outside body (eg. a judge or supervisory committee) which is responsible for the inspection of patients' care. This body should be authorised, in particular, to talk privately with patients, receive directly any complaints which they might have and make any necessary recommendations.

Involuntary placement in a psychiatric establishment should cease as soon as it is no longer required by the patient's mental state. Consequently, the need for such a placement should be reviewed at regular intervals.

Although no longer requiring involuntary placement, a patient may nevertheless still need treatment and/or a protected environment in the outside community. In this connection, the CPT has found, in a number of countries, that patients whose mental state no longer required them to be detained in a psychiatric establishment nevertheless remained in such establishments, due to a lack of adequate care/accommodation in the outside community. For persons to remain deprived of their liberty as a result of the absence of appropriate external facilities is a highly questionable state of affairs.

The organizational structure of health-care and social welfare services for persons with psychiatric disorders and mental disabilities varies from country to country. Nevertheless there is a tendency in a number of countries to reduce the number of beds in large psychiatric establishments and to develop community-based mental health units. We consider this is a very favourable development, on condition that such units provide a satisfactory quality of care.

It is now widely accepted that large psychiatric establishments pose a significant risk of institutionalisation for both patients and staff, the more so if they are situated in isolated locations. This can have a detrimental effect on patient treatment. Care programs drawing on the full range of psychiatric treatment are much easier to implement in small units located close to the main urban centre.

Finally, I would like to thank the organizers for providing me this opportunity of acquainting you with the work of our committee.

I can assure you, that persons in with mental disabilities are more and more getting into the focus of our work in our visits as well as in creating new jurisprudence.

Although CPT will always stick to the principle of confidentiality – and therefore little will be heard of it in the public – our task is to protect persons deprived of their liberty and to prevent any kind of ill-treatment or degrading treatment they might be in risk of.

I hope for good cooperation with all of you. Thank you for your attention.

FIRST SESSION

Mental health and human rights

PREMIERE SESSION

Santé mentale et droits de l'homme

MENTAL HEALTH AND HUMAN RIGHTS

Mr Stephen P. MARKS
François-Xavier Bagnoud Professor of Health and Human Rights
Harvard School of Public Health (United States)

"The highest attainable standard of physical and mental health".

Those words describe the basic objective of health policy. They also are the exact words used for the definition of the right to health in international human rights law. My purpose is to place the topic of the protection and promotion of the human rights of persons with mental disabilities into the broader context of the right to health and the relations between health and human rights. To do so, I will set out 1) some salient features of the human rights framework, 2) the meaning of the rights to health, and 3) the mental health dimensions of the international promotion and protection of human rights.

The Human Rights Framework

To understand mental health from a human rights perspective requires clarification of the precise and somewhat technical meaning of human rights in international affairs. Human rights are norms of national and international law governing the treatment by states and non-state actors of individual and groups. They derive their moral authority from shared ethical principles that motivate political institutions to adopt them and their legal authority from sovereign acts of states that accept them as binding law. The Council of Europe both administers legally binding norms, such as those contained in the European Convention on Human Rights or the European Social Charter, and promotes the emergence of new norms of human rights through its expert bodies, resolutions and other methods of giving voice to aspirational claims that may mature into justiciable and enforceable legally binding obligations. Legally binding human rights law requires governments to respect, ensure, promote and fulfil certain norms, with opportunities for persons denied their rights, nongovernmental organizations and various international agencies to obtain redress or change policy to achieve compliance with those norms. The aspirational claims include nonbinding norms through which advocates of various causes, such as rights of persons with mental disabilities (PWMD), introduce into non-binding statements, resolutions, declarations, guidelines and other texts of what lawyers call "soft law." Advocates for various causes draw upon human rights discourse in their effort to seek social change. Disability rights, and in particular rights of PWMD, are supported by a limited number of legally binding rules of domestic (normally constitutional) and international law and by several aspirational texts. However, the legal perspective is not the same as the human rights perspective. The human rights perspective provides a normative basis for a wide range of efforts to respect, protect and ensure the dignity, worth and well-being of people, of which the legal system is but one.

The human rights perspective should also be distinguished from ethical perspective, with which it shares a commitment to justice and right behaviour but involves difference sources, scope and methods for dealing with problems such as mental disabilities. Medical ethics deals with ethical behavior in the clinical relationship between a doctor and a patient. Public health ethics and bioethics deal primarily with the rationing of scarce health resources, social disparities, value issues of decision-making in health, and conditions of research on human subjects. In some cases bioethics and human rights support the same or similar norms, as in the case of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine,[1] or

---

[1] Adopted by the Committee of Ministers of the Council of Europe, on 4 April 1997

the UN Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.[2] Most human rights standards cover issues that are not addressed in bioethics and bioethics deals in depth with issues that human rights mechanisms only deal with marginally.

Other distinctions are useful to understand mental health from a human rights perspective, especially the difference between "rights" and "human rights." In ethics a right refers any entitlement, the moral validity or legitimacy of which depends on the mode of moral reasoning the ethicist is using. In law, a right is any legally protected interest. A person with a mental disability may have a right to special allocation of a certain sum. The right to that amount is legally protected but it is not a human rights. In human rights discourse, a human right is a higher-order right authoritatively defined using the expression "human rights" with the expectation that it carries a peremptory character. The right to protection from economic hardship due to disability is a human right, protected, for example by article xxx of the International Covenant on Economic, Social or Cultural Rights for all persons and by Rule 8 of the Untied Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities[3]

A further distinction is called for between the natural law and positive law foundations of human rights. As defined in natural law, a human right is usually considered inalienable, immutable and absolute, whereas in positive law it is dependent upon a political and legal process that results in a declaration, law, treaty or other normative instrument and may vary over time and be subject to derogations or limitations designed to optimize respect for human rights rather than impose an absolute standard. Human rights emerge from claims of people suffering injustice, and thus are based on moral sentiment, culturally determined by contextualized moral and religious belief systems.

People with mental disabilities do indeed suffer all sorts of abuse, stigmatization, marginalization, humiliation and discrimination but their voice has been difficult to hear, which explain the slowness in developing and applying appropriate norms to meet their needs. The leading study on human rights of persons with disabilities highlights this point by beginning with a chapter on the moral authority for change and a quotation from Bengt Lindqvist, UN Special Rapporteur on Disability:

> *Disability is a human rights issue! I repeat: disability is a human rights issue. Those of us who happen to have a disability are fed up being treated by the society and our fellow citizens as if we did not exist or as if we were alien from out space. We are human beings with equal value, claiming equal rights.*[4]

Once victims' claims are heard, the human rights norms to protect them become part of the social order when they are proclaimed by an authoritative body, through a process that is law-based, reflecting negotiated compromises and shifts over time, attaining progressively more responsiveness to the needs of the affected population and a higher degree of universality to the extent that representatives of virtually every nation participate in the norm-creating process. That is why the International Bill of Human Rights (consisting of the Universal Declaration of Human Rights (UDHR) of 1948, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), both of 1966), along with the other human rights treaties of the UN and of regional organizations, constitute the primary sources and reference points for what properly belongs in the category of human rights.

---

[2] General Assembly Resolution 37/194 of 18 December 1982

[3] General Assembly resolution 48/96 of 20 December 1993

[4] Gerard Quinn and Theresia Degener with others, *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*, United Nations, 2002, p. 13

The current catalogue of human rights consists of some fifty normative propositions enumerated in the international bill of human rights, extended by a score of specialized UN treaties, regional human rights treaties adopted by the Council of Europe, the European Union, the Organization of American States and the African Union. In addition hundreds of international norms have been adopted in the fields of labor, refugees, armed conflict, and criminal law. This corpus of human rights law, enriched by declarations, programs of action and other formulations of human rights in the process of becoming legally binding, is the source of the norms that properly fall with the category of international human rights.

The Mental Health Dimensions of the Right to Health

The human rights of person with mental disabilities—people who are different in mental capacities but equal in dignity and rights with all other humans—belong to a broader category of people with disabilities—which includes people who are different from the so-called norm in their physical capabilities. This broader category represents one-tenth of the entire population of the globe, or some 600 million people, according to WHO data. WHO also estimated that worldwide 450 million people have some form of mental or behavioural disorder, which corresponds to 12% of the global burden of disease.[5] The review of human rights norms applicable to PWMD will begin with the human rights standards emerging with respect to disabilities in general and then focus specifically on mental disabilities, noting in particular the current efforts of WHO and the OHCHR and offering some general conclusions.

The human rights framework takes on particular relevance for persons with mental disabilities when the meaning, scope and practical significance of the right to health are considered. The right to health as understood in international human rights law is defined in article 25 of the 1948 Universal Declaration of Human Rights (UDHR) ("Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services.”) and article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) (“the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”). Variations on this definition are found in most of the core UN and regional human rights treaties.

The European Social Charter devotes the following article to the right to health

Article 11 – The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed inter alia:

1 to remove as far as possible the causes of ill-health;

2 to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;

3 to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.[6]

Another article deals with disabilities, worded as follows:

---

[5] WHO, *Mental Health: New Understanding, New Hope*, World Health Report 2001, p. 3. (This figure is also cited by Paul Hunt, see below)

[6] Revised European Social Charter of 3 May 1996, Article 11

Article 15 – The right of persons with disabilities to independence, social integration and participation in the life of the community

With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

1 to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;

2 to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;

3 to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.[7]

In a General Comment on the Right to Health, the Committee on Economic, Social and Cultural Rights (CESCR) (created to monitor the ICESC) analyzed the normative content of the right in terms of accessibility, affordability, appropriateness and of quality of care, and specified the duties of the state to respect, protect and provide this right.[8] It also listed 14 human rights as “integral components of the right to health.”[9] In other words, these related rights defined to a large extent the determinants of health. With respect to mental health, the Committee interpreted paragraph 2 (d) of Article 12 of the Covenant (which refers to "The creation of conditions which would assure to all medical service and medical attention in the event of sickness") as covering “both physical and mental,” and including “the provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education; regular screening programmes; appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at community level; the provision of essential drugs; and *appropriate mental health treatment and care*. A further important aspect is the improvement and furtherance of participation of the population in the provision of preventive and curative health services, such as the organization of the health sector, the insurance system and, in particular, participation in political decisions relating to the right to health taken at both the community and national levels.”[10] Note both the explicit reference to mental health treatment and case and to participation, which would include presumably the participation of persons with mental disabilities and their families in these various means of provision of care.

The Committee specifically refers to mental disability as proscribed grounds of “discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement.”[11] It also refers to access of children to mental health services[12] and stresses “the need to ensure that not only the public health sector but also private providers of health

---

[7] Revised European Social Charter of 3 May 1996, Article 15

[8] Committee on Economic, Social and Cultural Rights, General Comment 14, E/C.12/2000/4, 4 July 2000, (“General Comment 14”), paras. 34-37

[9] General Comment 14, para. 3

[10] General Comment 14, para. 17 (Emphasis added)

[11] General Comment 14, para. 18

[12] General Comment 14, para. 22

services and facilities comply with the principle of non-discrimination in relation to persons with disabilities."[13] The committee does recognize that "coercive medical treatments" may be applied as "an exceptional basis for the treatment of mental illness… subject to specific and restrictive conditions, respecting best practices and applicable international standards, including the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care."[14]

With respect to public health infrastructures, the Committee considers that the state should promote and support "the establishment of institutions providing counselling and *mental health services*, with due regard to equitable distribution throughout the country."[15]

Human rights and determinants of mental health

The right to health does not mean the right to be healthy, since being healthy is determined in part by health care, but also by genetic predisposition and social factors. Respect for other human rights has a direct bearing on the right to health for persons with mental disabilities. Indeed the health of a person with mental disabilities is determined by more than a health care; the most salient social factors that contribute to healthy lives are affected by human rights deprivations. The field of social epidemiology has excelled at establishing correlations between discrimination based on race, class or gender, denial of education and of decent working conditions, as well as other factors that contribute directly to increased rates of mortality and morbidity. Discrimination and exclusion of persons with mental disabilities merit greater attention in social epidemiology as there is certainly clinical evidence that stigmatization, isolation and exclusion contribute to mental illness and studies at the level of populations show that those factors have a measurable impact on the prevalence and severity of mental illness. A rapid survey of some of these social determinants expressed in human rights terms may underscore the function of human rights as determinants of mental health.

Rights of existence

The first group of human rights of relevant to health relates to human existence and the integrity of body and mind. Thus, protecting individuals from deprivation of life and from physical or mental harm, as well as assuring the basic conditions of existence are fundamental to the realization of human rights. Only a brief mention can be made here of the right to life, to protection from genocide and to adequate standard of living.

Life: This right refers to the arbitrary deprivation of life. As will be discussed below, the mentally ill have been victims of mass deprivation of life. This right also suggests other complex issues for persons with mental disabilities relating to the moment at which the right to life is deemed to begin and taking of life by the state, i.e., the thorny issues of abortion and death penalty.

With respect to the first, bioethicists are divided on how to reconcile the reproductive right of a women to terminate a pregnancy—even if the motivation is that there is a virtual medical certainty that the foetus will result in a child with severe, crippling mental (or other) disabilities—and the alleged right to be born of a human being who is different but viable. Opponents of abortion have no difficulty supporting the right to life of all potential children. The issue is more complex for those who consider that the life of the potential child only merits protection after birth or beginning in late term pregnancy. With the technological capacity, such as ultrasound and advanced genetics, to determine early in pregnancy the likelihood of the child being born with severe handicaps, how free should the mother be to terminate the pregnancy? Some advocates of persons with disabilities argue that a pregnant woman whose child is expected to be born with severe mental disabilities should not have the right to an abortion because that potential child has the right to exist. Others argue that the woman has

---

[13] General Comment 14, para. 26.

[14] General Comment 14, para. 34

[15] General Comment 14, para. 36 (Emphasis added)

a right to decide whether or not to abort and for whatever reasons. It may be morally unacceptable for her to do so solely because she does not want a mentally disabled child. However, the criterion should be no different than when she makes the same decision because she does not want another mouth to feed or because she has been the victim of rape.

A rather odd twist on this problem is the case of Nicolas Perruche, whose mother contracted rubella during pregnancy, as a result of which he was born with severe mental and physical disabilities. Because he and his mother claimed that she would have had an abortion if doctors had correctly diagnosed the illness, France's highest court awarded him damages against the doctors for having let him been born. It has been correctly observed that rather than a matter of the “right not to be born” with mental or physical disability, the case is more about “the importance of *informed* procreative autonomy or reproductive freedom.”[16]

The death penalty is not prohibited under international human rights law but is discouraged by interpretation of the Covenant on Civil and Political Rights (ICCPR) and prohibited by an optional protocol the ICCPR and by protocols to regional human rights treaties. For those states that maintain the death penalty the UN Commission on Human Rights has urged them “not to impose the death penalty on a person suffering from any form of mental disorder or to execute any such person.”[17] The issue of a categorical exemption from the death penalty for people with mental disabilities is not necessarily that cut and dried. The complexities have been debated recently in the context of the 2002 decision of the Supreme Court of the United States, which held, in *Atkins v. Virginia,* that the execution of persons with mental retardation was unconstitutional in light of the growing recognition and consensus that those with mental retardation do not possess the requisite degree of culpability and cannot fully appreciate the consequence of their actions or comprehend the punishment that awaits them. Thus, the application of the death penalty to defendants with mental retardation is per se “cruel and unusual” and prohibited under the U.S. Constitution.[18]

Those individuals and organizations, like the American Association on Mental Retardation, who favored the majority in *Atkins*, stress the gullibility, poor impulse control, and susceptibility to pressure of persons with mental retardation, while the disabled-rights movement advocates “normalization, access, treating individuals as individuals.”[19] As one law professor commented, “if we accept the concept of blanket incapacity, we relegate people with retardation to second-class citizenship, potentially permitting the state to abrogate the exercise of such fundamental interests as the right to marry, to have and rear one’s own children, to vote or such everyday entitlements as entering into contracts or making a will.”[20] Of course, this contradiction between protecting persons with mental retardation from the death penalty while diminishing their status as having equal rights and responsibilities only exists in retentionist countries. It is a highly emotional issue because of other state-sanctions practices based on a eugenetic goal of eliminating mental disability from the gene pool.[21]

---

[16] Spriggs M, Savulescu J. Current controversy: The Perruche judgment and the right not to be born. *Journal of Medical Ethics* 2002; 28:63–4. J Savulescu Is there a “right not to be born”? Reproductive decision making, options and the right to information, *J Med Ethics* 2002;28:65–67

[17] Commission on Human Rights, resolution 2003/67, The question of the death penalty, adopted on 24 April 2003 by a recorded vote of 23 votes to 18, para. 4 (g)

[18] *Atkins v Virginia* 122 S.Ct. 2242 (2002)

[19] Margaret Talbot, “The Executioner’s I.Q. Test,” *The New York times Magazine*, June 29, 2003, p. 32

[20] Donald Bersoff, quoted in *id*., p. 33

[21] For example, the killing of retarded children, considered as “nature’s mistakes” was proposed in a prestigious scientific journal in the U.S. See Foster Kennedy, “The Problem of Social Control of the Congenitally Defective: Education, Sterilization, Euthanasia,” *Journal of the American Psychiatric Association*, vol. 99, pp 13-16 (1942), referred to in Robert N. Proctor, Nazi doctors, Racial Medicine and Human Experimentation, in George J. Annas and Michael A. Grodin, *The Nazi Doctors and the Nuremburg Code. Human Rights and Human Experimentations,* New York: Oxford Univ. Press, 1992, p. 24

Genocide: Following the extermination of six million Jews and several million Catholics, Gypsies, Communists, homosexuals and others at the hands of the Nazis in World War II, the General Assembly adopted in 1948 the Convention on the Prevention and Punishment of the Crime of Genocide, defining this crime as "acts committed with intent to destroy in whole or in part, a national, ethnic, racial or religious group, as such." Although disabilities are not included in the enumeration, during the Nazi era, a programme of "euthanasia" killings was instituted against the physically and mentally handicapped, who were viewed as "useless" to society, a threat to Aryan genetic purity, and, ultimately, unworthy of life. On July 14, 1933, the Nazi government instituted the "Law for the Prevention of Progeny with Hereditary Diseases," which required the sterilization of all persons who suffered from diseases considered hereditary, such as mental illness, learning disabilities, physical deformity, epilepsy, blindness, deafness, and severe alcoholism. By the end of the war an estimated 275,000 disabled people had been murdered by Hitler's Reich.[22]

Adequate standard of living: the international standard included protection from long-term disability, which, of course, means for persons with mental disability that they require state support when they are unable to provide for themselves due to their disability. The low priority given to long-term support for the mentally disabled, including in developed countries renders this right precarious. The standards of care defined in the 1991 Principles include the right of every patient "to receive such health and social care as is appropriate to his or her health needs, and … to care and treatment in accordance with the same standards as other ill persons."[23] The tragic reality is that mental illness and poverty are often elements of a mutually reinforcing downward spiral when fiscal restrictions are imposed on public health budgets.

Dignity: Both the basis for all human rights and—in a philosophically dubious assumption—often claimed as a right per se. If it means respect for the individual worth of each human being and not being subjected to humiliation, then it is difficult to find or even conceive of a violation of dignity without another human rights being violated, such as torture, discrimination, poverty, etc. As Székely notes for this seminar, degrading punishment or treatment has been define by the European Convention as measures aimed at humiliating or debasing the person concerned.[24] She notes that "treatment of a person of unsound mind can be considered degrading without there being any complaint from the person concerned." The 1991 Principles treat dignity as an autonomous right: "All persons with a mental illness …shall be treated with …respect for the inherent dignity of the human person"[25]

Human dignity is normally not an objective right but rather a basis for considering that certain defined behaviour (such as torture or discrimination) or circumstances (such as poverty) constitute violations of human rights, without an act of humiliation per se constituting such a violation. With respect to persons with mental disabilities, a strong case can be made for an objective right to dignity.

Identity: The right to identity as a human right is sometimes confused with the philosophical understanding people have or seek of their place in society and the cosmos. Human rights texts use the term in the sense of civil status. Therefore the issue of loss of legal capacity arises and the need for a high standard of due process where a person with mental disability is required, as provided in Principle 1.6 of the 1991 Principles.

---

[22] Information provided by the Holocaust Memorial at http://www.ushmm.org/research/library/index.utp?content=bibliography/handicapped/right.htm

[23] Principle 8 (1)

[24] Orsolya Székely, Involuntary detention and treatment of persons of 'unsound mind', manuscript. P. 6

[25] Principle 1(2)

Rights of autonomy

Autonomy rights are those that allow an individual to function according to his or her conscience and desires as long as their behaviour does not interfere with the rights and freedoms of others. The 1991 Principles explicitly acknowledge autonomy and a goal of treatment of persons with mental disabilities: "The treatment of every patient shall be directed towards preserving and enhancing personal autonomy."[26]

Civil liberties: The principal human rights in the category of civil liberties of concern to people with mental disabilities are freedom from arbitrary arrest or detention and freedom of movement and residence. These freedoms have to be balanced with the medial need for physical restraint and coerced institutionalization. The 1991 Principles stipulate in this regard:

> *Physical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose. All instances of physical restraint or involuntary seclusion, the reasons for them and their nature and extent shall be recorded in the patient's medical record. A patient who is restrained or secluded shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff. A personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient.*[27]

Further provisions relate to involuntary admission and retention of a person with mental illness in a mental health facility, which can only occur where "there is a serious likelihood of immediate or imminent harm to that person or to other persons; or … failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition…"[28] It should be noted that the World Network of Users and Survivors of Psychiatry (WNUSP) has taken strong exemption to the 1991 Principles, especially Principles 11 and 16, which WNUSP deems to contravene articles 5, 9, 13, 18 and 19 of the Universal Declaration of Human Rights.[29]

The human rights to autonomy of concern to people with mental disabilities also include freedom of thought, conscience and religion, freedom of expression, and the right to a fair trial, the right to privacy, freedom from discrimination and freedom of movement Rights to privacy, religious or belief and the like are among the rights persons with mental disabilities are expected to enjoy in mental health facilities.[30] The right of *privacy* also includes special protection of confidentiality of information concerning the person with a mental disability.[31] A particularly significant concern for the autonomy of persons with mental disabilities is *consent to treatment.* The patient must give informed consent except where "a qualified mental health practitioner authorized by law determines that it is

---

[26] Principle 9 (4)

[27] Principle 11 (11)

[28] Principle 16 (1)

[29] World Network of Users and Survivors of Psychiatry, Position Paper on the Principles for the Protection of Persons with Mental Illness, available at http://www.sre.gob.mx/discapacidad/paperwnusp.htm (visited on 29 July 2003)

[30] Principle 13

[31] Principle 6

urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons."[32] Numerous other safeguards are provided to ensure that treatment is carried out as far a possible with the patient's informed consent. The dilemma is, of course, that the ideas of being "informed" and of voluntarily consenting are matters of mental capacity, which, by definition, is diminished in the case of PWMD.

In addition, persons with mental disabilities are entitled to special safeguards through *legal process* to avoid arbitrarily losing legal capacity. In particular, a fair hearing is required before a legal representative can be appointed to act on behalf of a mentally ill person.[33]

There are two principal aspects of *discrimination* that are vital for persons with mental disability: 1) they should have equal enjoyment of rights with others and 2) special measures should not be considered as discrimination the 1991 Principles cover both.[34]

Rights of social interaction

The final group of human rights relates to social well being and the participation of individuals in social life. These include education, political participation, cultural participation and freedom of association.

Practices of countries regarding the *right to education* for persons with mental disabilities vary. In Denmark, for example, persons with mental disabilities are included in the education system, with special education where necessary, whereas in many countries they are not admitted to normal schools. Among the rights and conditions in mental health facilities, the 1991 Principles include facilities for education.[35] These principles are also quite explicit regarding the other principles rights relating to social life. Principle 3 on Life in the community, states, "Every person with a mental illness shall have the right to live and work, as far as possible, in the community." Principle 7 concerns the role of community and culture, stipulates:

> *1. Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.*
> *2. Where treatment takes place in a mental health facility, a patient shall have the right, whenever possible, to be treated near his or her home or the home of his or her relatives or friends and shall have the right to return to the community as soon as possible.*

---

[32] Principle 11 (8)

[33] Principle 1 (6) and (7) read: "6. Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision. 7. Where a court or other competent tribunal finds that a person with mental illness is unable to manage his or her own affairs, measures shall be taken, so far as is necessary and appropriate to that person's condition, to ensure the protection of his or her interest."

[34] 1991 Principles, Principle 1 (4) stipulates: "There shall be no discrimination on the grounds of mental illness."Discrimination" means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference undertaken in accordance with the provisions of these Principles and necessary to protect the human rights of a person with a mental illness or of other individuals."

[35] Principle 13 (2) (b)

> *3. Every patient shall have the right to treatment suited to his or her cultural background.*

Article 15 of the European Social Charter, quoted above, also refers to the promotion of "full social integration and participation in the life of the community" of persons with disabilities, which is relevant to the rights of social integration of persons with mental disabilities.

A final human rights concerning social life is *freedom of association,* which, in the case of persons with mental disabilities, protects their right to create advocacy organizations and to be heard, as has been quite effectively the case of Mental Disability Rights International or the Network of Users and Survivors of Psychiatry, as well as the thousands of local and national organizations that protect the interests of persons with mental disabilities.

Recent Developments regarding the Human Rights of Persons with Mental Disabilities

The specific standards that have emerged in the UN system and have evolved as our understanding of the issues improved. In 1971 the General Assembly Adopted the UN Declaration on the Rights of Mentally Retarded Persons,[36] which was followed twenty years later by The Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, which is a much more complete and improved text.

International norms relating to persons with mental disabilities have also been part of standard-setting for persons with disabilities in general. In 1993 the UN adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[37] These rules are monitored and the United Nations Special Rapporteur on the Standard Rules for the Equalization of Opportunities of Persons with Disabilities (Bengt Lindqvist), who was appointed by the Commission for Social Development. However, the norms and procedures that have been invoked on behalf of persons with disabilities range much farther and wider than the Standard Rules. In a study of some 300 pages on *Human Rights and Disability*, Gerard Quinn and Theresia Degener, with six colleagues brought together by the Disability Law and Policy Research Unit of the University of Galway, studied the human rights framework for disabilities, the use of each of the six main UN human rights treaties and the role of civil society, national institutions, UN machinery and a new convention.[38]

The inadequacy of government efforts to provide care or even to have a health policy programme for the mentally disabled is documented in The World Health Organization's *World Health Report 2001*, which was devoted to mental health in 2001.[39] The Division of Mental Health and Prevention of Substance Abuse has published at least 11 studies on various aspects of mental health treatment and programmes. The attention WHO is giving to the issue is not only invaluable from a public health perspective, but it has taken on the human rights perspective. In 1996, it published *Guidelines for the Promotion of Human Rights of Persons with Mental Disorders,* which is a 55-page set of questions and checklists to assist in applying the 25 principles of the 1991 Declaration.[40] The publication is part of WHO's "Initiative of Support to People Disabled by Mental Illness."

More recently, WHO has launched a *Project on Mental Health and Human Rights*, which focuses on mental health legislation. It is completing a manual on Mental Health Legislation, which will be used in a training program on mental health and human rights in November of 2003. The explicit use of human rights standards should be an invaluable component of WHO's movement to

---

[36] General Assembly Resolution 2856 (XXVI) of 20 December 1971

[37] Adopted by the General Assembly in Resolution 48/96 of 20 December 1993

[38] Gerard Quinn and Theresia Degener with others, *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability,* United Nations, 2002

[39] WHO, *Mental Health: New Understanding, New Hope,* World Health Report 2001

[40] WHO/MNH/MND/95.4

mainstream human rights, as evidenced not only by its recent publication on *25 Questions and Answers on Health and Human Rights* and a booklet on TB from a human rights perspective, but at the policy level.

A particularly noteworthy development is that the recently appointed Special Rapporteur on the right to health, Paul Hunt, has selected mental health as one of the critical issues he will examine. His mandate is:

> *(a) To gather, request, receive and exchange information from all relevant sources, including Governments, intergovernmental organizations and non-governmental organizations, on the realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health;*
>
> *(b) To develop a regular dialogue and discuss possible areas of cooperation with all relevant actors, including Governments, relevant United Nations bodies, specialized agencies and programmes, in particular the World Health Organization and the Joint United Nations Programme on HIV/AIDS, as well as non-governmental organizations and international financial institutions;*
>
> *(c) To report on the status, throughout the world, of the realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, in accordance with the provisions of the instruments listed in paragraph 4 above, and on developments relating to this right, including on laws, policies and good practices most beneficial to its enjoyment and obstacles encountered domestically and internationally to its implementation;*
>
> *(d) To make* recommendations *on appropriate measures to promote and protect the realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, with a view to supporting States' efforts to enhance public health.*[41]

In his first report, Hunt sets out his priorities for implementing this mandate. One section is devoted to issues relating to discrimination and stigma in the context of the right to health. In this regard, he notes:

> *Social inequalities, fuelled by discrimination and marginalization of particular groups, shape both the distribution of diseases and the course of health outcomes amongst those afflicted. As a result, the burden of ill-health is borne by vulnerable and marginalized groups in society.*[42]

And he adds:

> *At the same time, discrimination and stigma associated with particular health conditions such as* ***mental disabilities****… tend to reinforce existing social divisions and inequalities.*[43]

The Special Rapporteur also expressed alarm at:

---

[41] Commission on Human Rights resolution 2002/31, The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, adopted on 22 April 2002, para.5

[42] Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31, U.N. doc. E/CN.4/2003/58 (13 February 2003), para. 59

[43] Id. (Emphasis added)

> *the wide range of human rights violations that reportedly occur in some institutions designated for the care and treatment of persons with mental disorders. These violations include torture and other cruel, inhuman or degrading treatment, such as sexual exploitation. The Special Rapporteur also notes the stigma and discrimination surrounding mental disorders, as well as the real or deemed incapacity of persons with mental disorders to take decisions on account of their illness - it is the combination of these interrelated issues that makes persons with mental disabilities particularly vulnerable to violations of their human rights. .*[44]

He expressed concern:

> *that in many States mental health care often consists primarily of large psychiatric institutions, with limited provision of community-based treatment and care.*[45]

But most significantly is the separate treatment he intends to devote in his report to mental health. He concludes by saying he will "give particular attention to the right to mental health, without duplicating or overlapping with the work of other relevant international bodies."[46]

The current focus of attention in the United Nations system regarding the disabled is the draft United Nations Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. The General Assembly decided in 2002 "to establish an Ad Hoc Committee, open to the participation of all Member States and observers of the United Nations, to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development."[47] The contribution from the High Commissioner's Office has stressed the rights and dignity of persons with disabilities based on the holistic approach of social development, human rights and non-discrimination.[48]

The government of Mexico organized the Inter-regional expert meeting on International Norms and Standards relating to Disability, which took place from 10 to 14 June 2002, following which the government submitted "Elements for a future United Nations Comprehensive and Integral Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities."[49] According to that draft "disability" means "a physical, mental (psychic), or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment."

The Ad Hoc Committee met for the first time in New York from 29 July to 9 August 2002. It met again on 16-27 June 2003 and decided to establish a Working Group to present draft text for negotiation. The process is thus underway for a convention to be ready for adoption in 2004 or 2005. On 12 December 2002, the United Nations NGO Committee on Mental Health met in New York to discuss the draft convention and the interests of those with psychiatric disabilities in a new

---

[44] Id., para. 93. Professor Hunt cites as an example Mental Disability Rights International, *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo,* MDRI, 2002

[45] Id., para. 92

[46] Id., para. 94

[47] General Assembly Resolution 56/168. Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, adopted 19 December 2001

[48] See Report of the High Commissioner, E/CN.4./2002/18, Add. 1

[49] Letter from the Government of Mexico to the Secretary General dated 15 July 2002, U.N. doc. A/57/212

Convention.[50] Several views were expressed by mental health advocates. Some, like the World Network of Users and Survivors of Psychiatry, continue to oppose involuntary commitment and forced treatment and believe that the Convention should the persons with mental illness submit only on a voluntary basis to mental health treatment.[51] Others considered that treatment should be improved through specific legal requirements for short-term care, independent review before admission to care, and an independent monitoring commission to hear individual complaints should be included in the mental health provisions of the Convention.

Of course, mental disabilities are not the only concern of the drafters and all those concerned with protection of human rights of persons with mental disabilities will have to be vigilant that the convention genuinely furthers their human rights.

CONCLUSION

This brief overview of a human rights perspective on mental health suggests some insights that might guide future research and policy determination. The first is that, as we have learned in developing a human rights approach to HIV/AIDS, the effective and meaningful participation in the deliberations of the persons affected is essential both as an exercise of human rights and for the quality of the outcome. The inclusion of NGOs representing persons with mental disabilities in the drafting of the disabilities convention is a positive sign.

Second, standard-setting and monitoring of human rights of persons with mental disabilities are moving at an accelerated pace in the European system and in the UN. WHO has used a human rights approach to mental health and merits support in continuing and expanding in that direction. With a change in leadership, it will be all the more important not to lose the momentum the human rights perspective has gain in that organization. The UN special Rapporteur on the right to health has decided to prioritize mental health in carrying out his mandate and merits the full support of scholars, officials and activists. The resources available to him are inadequate to carry out much work on the problems of human rights and mental health and others should contribute to his efforts. The draft convention on disabilities has the potential of advancing the interests of persons with mental and other disabilities provided that the norms and mechanisms agreed upon respond adequately to those interests.

Finally, one needs to ask what a human rights perspective adds to the legitimate struggle of people with mental disabilities to function in society with dignity. Mental health is a social problem like many others and the normal social and political processes of health service providers could be considered the appropriate arena, without invoking a human rights perspective. The short answer is the general proposition that a human right perspective transforms “beggars into claimants”. In other words, support for the needs of people with mental disabilities ceases to be a matter or charity and of dependence on the part of the affected individuals and become a matter of the exercise of their rightful place as humans, equal in dignity and rights with all of us.

---

[50] See report of The World Federation for Mental Health at http://www.wfmh.org/newsletter/nl024/newunconvent024.html

[51] For WNUSP’s suggested amendments to the Mexico draft, see http://www.wnusp.org/docs/mexico_suggestion.html

COMPULSION, CONFIDENTIALITY AND CONSENT – THREE CURRENT DILEMMAS IN HUMAN RIGHTS AND MENTAL DISORDERS

Lord ALDERDICE
Speaker of the Northern Ireland Assembly
Consultant Psychiatrist

There are already many international human rights instruments and some of the articles they contain are of particular relevance to persons suffering from mental disability however, though we may relatively easily set down ideals, implementing them is another matter entirely. A Right to Health for example is easily proclaimed, but how can it be obtained, for it is not the same thing as a Right to Health Care. In the case of mental health in particular there is no unanimity about what causes mental illness. There is also little agreement about what management or treatment will best promote mental health or a return to mental health in any particular individual with mental disabilities – even setting aside the many sad circumstances where there is no prospect whatever of achieving good mental health, no matter how excellent the care and treatment available.

I do not however propose to dwell on such wide issues of debate but rather, at the start of this important consultation I would like to present three specific areas that concern me greatly in the field of Mental Disorder and Human Rights. They are serious current issues, though in some of our countries they may be a more present danger than in others, and I would readily admit that I am heavily influenced by developments in the United Kingdom where I live and work as a psychiatrist and as a legislator with an interest in Human Rights. At the same time I have good reason to believe that my concerns are widely shared by other professional and voluntary colleagues involved in mental health care, and by a number of human rights activists.

I must also make clear that in presenting these concerns I am very aware that they could be misunderstood as being in conflict with some more traditional preoccupations in this field. I do not see them in this way, but rather hope that what I say will be set alongside, rather than in opposition to, long-standing commitments.

The first threat to the rights of mentally disordered persons which I discern comes from the growth of a risk averse society. It is now commonplace to find that any unfortunate happening is followed by an attribution of blame, in which it is assumed that the adverse event occurred because someone in authority failed in his or her duty to prevent it. If a child is abused the focus of blame sometimes shines less on the abuser than on an under-resourced social services department which failed to detect and prevent it. Whether or not it is found that there was a failure to observe current best practice, the post hoc enquiry will inevitably produce recommendations of further regulations and monitoring, which restrict the freedom of carers and those cared for without much evidence of effectiveness. A very obvious outcome of this process, which is evident in every aspect of public and professional life, is now apparent in the recent Draft Mental Health Bill in the United Kingdom. This proposes to widen the definition of mental disorder to include any disorder where mental functioning is impaired. This could include disorders such as diabetes and epilepsy, as well as learning disability, alcohol and drug abuse and sexual deviancy. It would then create a legal requirement on mental health professionals to compulsorily refer and admit to mental hospitals for a one month assessment anyone who fulfils the requirements that they are suffering from a mental disorder, warrant provision of treatment and are a substantial risk to themselves or anyone else, but notably without any requirement that this be in the best interests of the patient, or that it is of direct therapeutic benefit to the patient.

The reason for this approach is the wish of the current British Government to ensure that people with what is described as Dangerous Severe Personality Disorder (DSPD) are able to be incarcerated by psychiatrists before they commit any crimes, rather than by courts through due process after a breach of the criminal law - a prospect that horrifies the Royal College of Psychiatrists and its members. Recent articles in Royal College of Psychiatrists publications have suggested that even within high-risk groups 100 patients would have to be detained unnecessarily to prevent one suicide and 2000 people detained to prevent one homicide. It is of note that in expressing its concerns about these proposals the Royal College of Psychiatrists calls in aid the standards of the Council of Europe, emphasizing the importance and immediate relevance, I believe, of these deliberations here in Copenhagen. In short the historic fear of the mentally ill combined with a more recent generalized aversion to uncertainty and risk is opening the door to illiberal and authoritarian legislation which will profoundly adversely affect the rights of people with a wide range of disorders, and will likely overburden health care systems to the point of them being overwhelmed. There are other ways in which the reasonable concerns of the population could be addressed, and which in the long run would be likely to be much more effective. One such line would be to adopt a more sensitive approach to the assessment of impaired decision-making by patients, and by maintaining professional flexibility under a ‘least restrictive alternative’ requirement for compulsory treatment.

My second concern is based on a more recent development which emerges from the catastrophic events of September 11, 2001. Many of us, even as we watched the unfolding of the horror before our eyes in real time on satellite television, felt a cold chill as we sensed that the terrible suffering of the families of those killed and the fear generated in the community by the prospects of further terrorist attacks, would be used to justify a rolling back of the human rights agenda. We did not have long to wait. Around the world Justice, Home Affairs and Interior Ministries dusted down proposals that had lain on shelves for years because of their public unacceptability, and presented them to Ministers spiced up with briefs that made them relevant to the current crisis. One important example was that loss of personal privacy and confidentiality was presented as a small price to pay for security against another 9/11 or worse. Combined with a more long-standing and constructive view that sharing of patient information between agencies was the way to better health care for patients, there is now pressure to create a legally binding compulsion on mental health care workers, including doctors, to provide confidential information not only to other health care agencies, but also to the police. I believe that not only is this straining to the limit the interpretation of Article 8 of the ECHR, but it will inevitably lead to patients with-holding information in ways which will profoundly damage the prospects for their treatment, and in the end for public safety.

My third area of concern is perhaps the most difficult to outline, but the most essential to an understanding of the dilemmas of human rights and mental health. The stigma of mental disorder and the disabilities and discrimination suffered by mentally disordered people are in some measure shared by many other groups of disabled people. Working together in campaigns to improve human rights using a common disability model has led to the achievement of significant progress in the welfare of all disabled people and more can still be achieved by pursuit of this important path. At the same time it must be recognized that mental disorder makes a more fundamental attack on the person than any other disability for it damages some of those aspects of the person which we regard as distinctively human. One of the central features of our work in human rights is our determination to maintain the freedom, dignity and autonomy of the individual person, and all of these are jeopardized in mental disorder. Let me take as a brief example the autonomy of the person suffering from a psychotic illness. Their autonomy, an essential feature of their human rights, is not only at risk from external compulsion, neglect or injury, but also damaged to a greater or lesser extent by the dissolution of their mental functioning from within.

It is here that the principle of human rights is most important and most complex, but this is also the point where a legal implementation is most difficult. It is not easy to balance the welfare of the patient in a psychotic state against that of their family, even when we set aside the grosser and less common cases where the risk of violence is apparent. The patient's capacity to think freely is damaged by the process of dissolution of their mental function by the illness. Their relation to reality and their volitional capacities are disturbed. This situation is also fluid. At times they may be less incapacitated, and at other times profoundly disturbed. The law generally wants to know whether the patient wants this or that - yes or no - and is not generally constructed to be sympathetic to the double book-keeping which is an essential feature of much of human life and all mental illness. The fact that a patient may say one thing, and mean another, or say one thing at one time and then something completely contradictory in five minutes time, is common-place, but a legal conundrum. There have been a number of efforts to address this. The most obvious and least satisfactory is to assume that the patient, if not deranged, would have the same view as their medical attendants. This may be made more acceptable by broadening the field to include the family or close confidantes. In such a case the doctor would consult with colleagues and with the patient's circle of family and friends, and then assume that their shared judgement approximates to what the patient would have wanted had they been well. We only need to reflect for a minute on our own feelings about our wishes being subjected to such a set of criteria to know that it is a very crude approximation. An improvement in the context of a relapsing illness may be the adoption of 'Advance Statements' by patients, in which they may declare in a signed statement how they would wish matters to be handled in the event that they fell ill again. This may not just be in connection with their medical care, and whether they should be prescribed medication against their will as expressed during a period of incapacity, but also matters such as childcare arrangements and their financial affairs, which may be particularly problematic during certain acute psychotic episodes.

Such 'Advance Statements' do not entirely resolve the problem however, even in those recurrent conditions where they could be applied, for they do not of themselves take account of the complexities of management and judgement which are necessary, and also the fact that in illness what emerges is not just an expression of illness but also a release of certain inhibited parts of the personality - for good and for ill. Close relationships have the possibility of being part of the patient's problem as well as part of their sustaining support during difficult times.

These then are the three current issues which I wish to draw to your attention – Treatment under Compulsion, especially where it is not demonstrably effective or in the interest of the individual patient concerned - Limits to Confidentiality, and the potentially disastrous consequences this may have not only on treatment but on the very public safety in whose service it is demanded, and - the Problem of Achieving Consent and the door this issue opens into the dilemmas of using legal instruments to address the conflicts and complexities of the mind, especially in serious mental illness.

These three dilemmas which I have tried to sketch out are all expressions of what Baroness O'Neill described in the Reith Lectures last year as 'A Question of Trust'. She pointed out that for the last fifty years we have tried to use human rights and democratic accountability to address the gross breaches of trust represented by human rights abuses, inequity of social and economic opportunity and the damage caused by war, criminal acts, misjudgements and simple tragedy. Unfortunately human rights law and democratic accountability have not succeeded in regenerating the trust that was lost. Rather trust has been replaced by them as the basis of public relationship, and trust is now almost absent in political, professional and public life. Relationships of course cannot survive in the absence of trust and no life is worth living, or perhaps ultimately even possible to live, without some relationships of trust. In pursuing our concern for the human rights of those suffering from mental disorder we must try to ensure that the valuable mechanisms which we are using for the protection of those who are human, does not itself come to jeopardize the very humanity which it seeks to protect.

SECOND SESSION

Restrictions on liberty : procedures and criteria for involuntary and non-voluntary placement and treatment

DEUXIEME SESSION

Restrictions à la liberté : procédures et critères pour le placement et le traitement involontaires et non-volontaires

INVOLUNTARY DETENTION AND TREATMENT OF PERSONS OF “UNSOUND MIND”

Orsolya SZÉKELY
Lawyer at the Registry of the European Court of Human Rights

1. Introduction on the European Court of Human Rights

Opened for signature in 1950, the Convention for the Protection of Human Rights and Fundamental Freedoms set up a mechanism for the enforcement of the obligations undertaken by the Contracting States: initially, the European Commission of Human Rights, the part-time European Court of Human Rights and the Committee of Ministers of the Council of Europe. The Convention enabled individuals to bring complaints alleging a violation of their rights under the Convention against the Contracting States (originally only against those which accepted individual complaints). Protocol No. 11 to the Convention brought several changes into the court-system: it made the acceptance of the individual complaints compulsory and replaced the part-time Court and the Commission with a full-time Court.

Both the Commission and the Court decided in numerous cases concerning persons with mental disability. Article 1 and 14 of the Convention state that the Contracting Parties shall secure to everyone within their jurisdiction the Convention rights and freedoms without discrimination on any ground. Primarily on the basis of the Court’s case-law, my intention is to present those situations in which the rights and freedoms of a person with mental disability might be restricted.

2. Restrictions on the right to liberty and security, Article 5 of the Convention

> “1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:
>
> (a) the lawful detention of a person after conviction by a competent court;
>
> (b) the lawful arrest or detention of a person for non- compliance with the lawful order of a court or in order to secure the fulfilment of any obligation prescribed by law;
>
> (c) the lawful arrest or detention of a person effected for the purpose of bringing him before the competent legal authority on reasonable suspicion of having committed an offence or when it is reasonably considered necessary to prevent his committing an offence or fleeing after having done so;
>
> (d) the detention of a minor by lawful order for the purpose of educational supervision or his lawful detention for the purpose of bringing him before the competent legal authority;
>
> (e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;
>
> (f) the lawful arrest or detention of a person to prevent his effecting an unauthorised entry into the country or of a person against whom action is being taken with a view to deportation or extradition.
>
> 2. Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him.

> 3. Everyone arrested or detained in accordance with the provisions of paragraph 1 (c) of this Article shall be brought promptly before a judge or other officer authorised by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release pending trial. Release may be conditioned by guarantees to appear for trial.
>
> 4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.
>
> 5. Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation."

2.1. "Persons of unsound mind"

Article 5 of the European Convention on Human Rights guarantees the right to liberty and security. However, according to paragraph 1 (e) of that Article, the liberty of "persons of unsound mind" can be restricted.

So what does the expression "persons of unsound mind" mean? A person whose behaviour or views deviate from the "norms prevailing in a particular society" cannot be detained under Article 5 § 1 (e) simply for these reasons. Already in the *Winterwerp* case the Court pointed out that the term should not be interpreted extensively, leaving it open for the States to develop their legislation in accordance with the improvements of psychiatry and the more thorough understanding of people with mental disorder. Although the text of the Convention was drafted more than half a century ago, it is a living instrument, which is reflected in the Court's continuously developing case-law.

2.2. "Lawful" detention and involuntary treatment

The detention of "persons of unsound mind" can be ordered in two situations. As the Court expressed in the case *Guzzardi v. Italy* their detention is not only justified if they are of danger to public safety, but also if their own interest makes it necessary. In both situations, the detention has to have a legal basis in domestic law. Following its rule of "margin of appreciation", the Court allows the State to a certain extent, to decide for itself how to set the criteria for the detention of people with mental disorders. However, the domestic regulations should at least be in conformity with three minimum requirements which were established in the *Winterwerp* case:

- an objective expert must reliably show that the person is of unsound mind;
- the persons' disorder must be so severe that his or her detention is justified (either because he or she is of danger to the public safety or to his or her own health); and
- the disorder should persist throughout the entire time of his or her detention.

Two important questions – when should a psychiatric examination be carried out and who should do it – have been examined in several cases by the Court.

When?

A psychiatric examination should normally be carried out before a person is detained. Sometimes the circumstances might call for emergency detention, however; in such a situation a medical confirmation, at least of a provisional character, must be obtained within the shortest possible time. In the case of *Varbanov v. Bulgaria*, the public prosecutor ordered that the applicant should undergo an involuntary psychiatric examination and be put in detention, without any expert opinion having been obtained. The order was not justified by any emergency situation. Moreover, the applicant presented a psychiatric opinion from a doctor, stating that he was mentally healthy. The Court held that Article 5 had been violated.

In the case of *Nowicka v. Poland*, which concerned private prosecution brought against the applicant by her neighbour, the applicant's mental health was called into question. Having refused to undergo a psychiatric examination, she was arrested and detained for a total period of eighty-three days. The examination was delayed several times which – the Court said – violated her right to freedom.

Who?

The examinations should always be objective and carried out by an independent authority from that ordering detention. It is for the individual state to decide whether to establish a permanent Mental Health Board or to appoint medical experts on a case-by-case basis. However, the Court has set a minimum requirement for that domestic regulation: a psychiatric expert cannot act as a judge in the same case; otherwise the judiciary's impartiality is not guaranteed (*D.N. v. Switzerland)*.

In addition to the three minimum requirements of domestic law which I mentioned earlier, I would like to point out a key safeguard aimed at preventing the abuse of power when someone is deprived of his or her liberty: Everyone who is arrested, detained or subjected to involuntary medical treatment shall be informed of the reasons therefor promptly, in a language he understands. In case the person's mental disorder is so severe that he does not understand the measures that are taken against him, someone representing him should be informed.

In the case of *Van der Leer v. the Netherlands*, the applicant was a voluntary patient in a psychiatric hospital. A court ordered her compulsory confinement, without informing or hearing her at the time of the decision. The European Court held that neither the way she was finally informed, nor the length of the proceedings in which her detention was decided complied with the Convention's provisions.

2.3. "Procedure prescribed by law" and the absence of "arbitrariness"

In relation to Article 5 of the Convention, the Court first examines whether the detention of a person with mental disorder was ordered in accordance with domestic regulations. The detention of persons of unsound mind must be ordered, reviewed and terminated "in accordance with a procedure prescribed by law".

Normally, as it has been stated in numerous decisions by the Commission and the Court, it is in the first place for the national authorities, notably the courts, to interpret and apply domestic law. However, when the Convention refers directly back to that law – as it does in Article 5 § 1 (e) – the Court has jurisdiction to make a certain review of domestic law.

Here I would like to mention only a few examples when the Court found that the applicant's rights under Article 5 were violated by the infringement of procedural rules:

- A prosecutor's order to detain persons who allegedly were of unsound mind, which was not issued according to a procedure prescribed by the law, but based on an unpublished instruction (*Varbanov v. Bulgaria*).
- The lack of decision-making power of the detention-reviewing body (*Benjamin and Wilson v. the United Kingdom*).
- The failure to provide legal assistance for a person suffering from severe mental disorder in proceedings concerning review of detention (*Megyeri v. Germany*).
- The domestic courts' failure to carry out the review proceedings within a reasonable time (eight weeks from lodging the application) (*E. v. Norway* and *Musial v. Poland*).
- The domestic court's failure to hear the person whose confinement was ordered, and to inform her of the decision (*Van der Leer v. the Netherlands*).

After reviewing a domestic decision's compliance with the national substantive and procedural rules, the Court examines the decision in the light of the purpose of the restrictions imposed on the person concerned. The absence of arbitrariness is a necessary element of lawfulness. To avoid the arbitrariness of the detention of persons of unsound mind, it has to be compatible with therapeutic requirements. Any confinement of persons of unsound mind must be carried out in a "hospital, clinic or other appropriate institution".

In an early case, the Court did not find a violation when the applicant's transfer from a high security hospital to a less restrictive one was delayed for 19 months after it had been ordered. Despite the fact that the applicant's mental status would have justified his confinement in a less severe hospital, the Court found that since the applicant was, in any case, detained, the delay did not raise an issue under Article 5 § 1. As it stated: Article 5 § 4 "does not guarantee a right to judicial control of the legality of all aspects or details of the detention" (*Ashingdane v. the United Kingdom*).

The Court's approach seemed to be more sophisticated in the case of a Belgian applicant (*Aerts v. Belgium*). He claimed that his detention in a psychiatric wing of a prison was unlawful, as he did not receive regular medical attention and the environment was not therapeutic. The Court found a violation. As in that case, the reports of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) can give the Court reliable information as to the conditions in the prison or institution in question.

In many cases applicants complain about the conditions in a psychiatric institution or about certain types of treatment. These issues certainly fall outside the scope of Article 5. However, they might be examined under Article 3 of the Convention.

3. Prohibition of inhuman or degrading treatment or punishment, Article 3 of the Convention

> "No one shall be subjected to torture or to inhuman or degrading treatment or punishment."

What does inhuman treatment or punishment mean?

Ill-treatment falls within the scope of Article 3 only if it attains a minimum level of severity. The level of severity depends on the circumstances of the case, such as the duration of the ill-treatment, the sex, age and mental health of the applicant, the mental or physical effects, etc. (*Ireland v. the United Kingdom*). Inhuman treatment causes less intense suffering to a person than torture. It can have different forms: physical assault, use of psychological pressure, the detention of a person in inhuman conditions or the lack of proper medical care.

When the detention concerns mentally ill persons, their vulnerability and their possible inability to complain or express how they feel about their treatment must be taken into account. When they are detained the State has a positive obligation to comply with the purpose of their detention, by, for instance, providing proper care and treatment. Therefore, obligatory treatment cannot in itself be regarded as inhuman, but that might be the case if it does not fulfil the aim of Article 5 § 1 (e) of the Convention. In the case of *Herczegfalvy v. Austria*, the applicant's obligatory treatment was ordered as he was severely mentally ill and dangerous to the public. Although he refused to accept any medical treatment, he was force-fed and he was attached to a security bed for weeks. The Commission and the Court had differing opinions on whether the length of the use of a security bed was justified. While the Commission stated that there had been a violation of Article 3, the Court held that there had been no violation of the same Article, as the examined evidence was not sufficient to prove that the treatment was not medically necessary according to the psychiatric principles generally accepted at the time.

The applicant's complaint concerning his forced feeding was found to be justified by both the Commission and the Court. As the Commission pointed out, although the applied measures might have been humiliating, their aim had been to protect the applicant's life, which prevailed over considerations related to Article 3.

How can degrading treatment or punishment be differentiated from inhuman?

The object of degrading treatment or punishment is to "humiliate and debase the person concerned" which, therefore, "adversely affects his or her personality in a manner incompatible with Article 3 of the Convention" (*Albert and Le Compte v. Belgium*). A person can be humiliated not only in front of others but also in his or her own eyes. Treatment which creates feelings of fear, anguish and inferiority capable of humiliating or debasing a person and this way possibly breaking his moral or physical resistance or making him act against his will, is also degrading (*Ireland v. the United Kingdom*). While in most of the cases under Article 3 the Court examines whether the degrading treatment imposed on a person has any ill-effects, treatment of a person of unsound mind can be considered degrading without there being any complaint from the person concerned.

In the case of *Keenan v. the United Kingdom* the applicant was suffering from a chronic mental disorder and had a medical history which showed suicidal tendencies. A few weeks before his scheduled release from a four-month imprisonment, he assaulted two prison officers when he was told about his release. The prison doctors, with no psychiatric experience, failed to contact Mr. Keenan's psychiatrist before ordering his punishment: isolation without regular surveillance and the addition of 28 days to his imprisonment. A few days later he committed suicide. The Court held that the failure to provide psychiatric treatment and the lack of effective monitoring amounted to a violation of Article 3.

4. Restrictions on the right to respect for private life, Article 8 of the Convention

> "1. Everyone has the right to respect for his private and family life, his home and his correspondence.
>
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

Article 8 of the Convention recognises the right to respect for private and family life including the respect of home and correspondence. However, these rights are not absolutely guaranteed; a public authority may interfere with them if the interference

- is in accordance with law;
- pursues a legitimate aim (which can be the protection of national security, the prevention of disorder and crime, the protection of health or morals or the rights and freedoms of others, etc.); and
- is necessary in a democratic society.

In addition to its obligation not to interfere with the rights under Article 8, the State might also an obligation to take positive action for the protection of these rights. This duty must be fulfilled not only in relation to public authorities, but also when violation of Article 8 might occur on the basis of a private agreement (*Hokkanen v. Finland*). The application of this rule becomes important in relation to the involuntary placement or treatment of mentally disordered or elderly people, or minors. Involuntary placement in private homes, if they are not given proper care, might result in the responsibility of the State.

While dealing with the complaints under Article 8, the Court makes an assessment of the proportionality between the interest of the State and the right of the individual. Any psychiatric treatment imposed on persons of unsound mind is clearly an interference with their rights under Article 8 of the Convention. However, the involuntary placement or treatment does not in itself violate someone's private life, if the three requirements, mentioned earlier (see page 3.) are met (*Herczegfalvy v. Austria*).

In the end, I should mention a few examples of complaints concerning Article 8 which have been examined by the Commission and the Court.

In the domain of private life, the case of *Y.L. v. France* (Commission) concerned a situation where a treated person could not chose the psychiatric institution or the psychiatrist. In a case against Austria cited above, Mr *Herczegfalvy* complained that he was forced to undergo medical treatment in the institution against his will. No violation of Article 8 was found in either case. However, in the case of *Herczegfalvy,* another issue arose under Article 8 concerning the applicant's correspondence. His letters were given to the curator, who selected those actually to be sent to the addressees. The Court held that, in this respect, the applicant's rights had been violated.

Furthermore, several cases concerning *inter alia* the distance between the institution and the family's residence or the right to receive visits gave rise to issues with repercussions on the applicant's right to respect for his family life. Although the case of *Nasri v. France* was introduced by a person born deaf-and-dumb rather than by someone mentally disabled, it can nevertheless be related to the discussed topic. Mr Nasri, an Algerian national, lived in France with his family, of whose members were mostly French nationals. On account of his having committed a serious crime (gang rape) and being a multiple recidivist, his deportation was ordered. The Court found that, despite the serious crime, Mr Nasri's deportation would unjustifiedly interfere with his family life, as he was able to achieve a minimum social and psychological equilibrium only within his family.

THIRD SESSION

Integrity and dignity

TROISIEME SESSION

Integrité et dignité

SAFEGUARDING PEOPLE WITH MENTAL HEALTH PROBLEMS AGAINST ABUSE

Prof. Hilary BROWN
Professor,
Canterbury Christ Church University

Abstract

This paper draws on a recent Council of Europe publication on safeguarding disabled people against abuse. The presentation examines the common agenda articulated by all disabled people and their representatives as well as very specific concerns voiced by mental health service users. The report offered an overview of research and urged governments to collaborate in generating comparable data and sharing examples of best practice.

Introduction

This paper presents the findings and recommendations of a recent working group exploring the safeguards needed to protect all disabled people, including those with mental health problems, against abuse. The report acknowledges that the issues are not uniform, and cannot be dealt with in the same "blanket" way for all groups. Whilst endorsing this view, I want in this paper to describe and highlight a very broad set of concerns about violence, vulnerability and social exclusion, - issues around which mental health service users can indeed make common cause with other interest groups within the disability movement.

The group drew up a definition of abuse that was deliberately broad and inclusive, mindful of the fact that discrimination against disabled people is inextricably linked to abuse.

The report provides a working definition of abuse that includes physical and sexual abuse, psychological harm and financial abuse and neglect/ abandonment whether physical or emotional. It addressed abuse in all settings with a particular concern for people still living in closed institutions and for those abused by people in positions of authority. It was concerned with the failure to access equivalent health care on behalf of people with disability even where they seem to be living in settings that disguise themselves as hospitals or clinics. Special concern was voiced for those who are doubly disadvantaged including women and girls with disabilities and disabled people from ethnic and refugee communities or from war torn countries. The report considered capacity and consent as key issues in determining whether acts are abusive or whether they represent valid choices made by disabled people whose rights to make decisions and take risks are equal to those of other citizens. The scope of concerns raised by member states included

- ☐ seriously inadequate care and attention to basic needs including nutrition, health care and access to educational and social opportunities;
- ☐ individual acts of cruelty or sexual aggression by persons who are in the role of care givers;
- ☐ breaches of civil liberties such as incarceration without due process, "enforced cohabitation" in group homes or institutions, prohibition of sexual relationships or marriage, lack of privacy or intrusion into or interruption of mail or telephone calls or visits, in institutional or family settings and / or continued isolation from sources of support or advocacy;

- ☐ acts of bullying or random violence within community settings , some of which may represent more extreme forms of generally held prejudice against people with disabilities or, of greater concern, global ideologies which are inimical to disabled persons;
- ☐ practice by individual staff which falls well outside, or below, accepted professional norms;
- ☐ abuses by other service users within service settings where attention had not been paid to safe groupings or sufficient supervision was not available to ensure safe placements;
- ☐ authorized treatments and interventions which are not in the person's best interests and/or which rest on an inaccurate or incomplete understanding of their condition and needs, for example punitive responses to challenging behaviour, seclusion, unconsented ECT, or aversive behavioural programmes;

To summarise abuse is defined as :

Any act, or failure to act, which results in a significant breach of a vulnerable person's human rights, civil liberties, bodily integrity, dignity or general well-being; whether intended or inadvertent; including sexual relationships or financial transactions to which the person has not or cannot validly consent, or which are deliberately exploitative.
Abuse may be perpetrated by any person, (including by other people with disabilities) but it is of special concern when it takes place within a relationship of trust or unequal power characterised by
powerful positions based on their legal, professional or authority status,
unequal physical, economic or social power,
inequalities of gender, race, religion or sexual orientation and /or
responsibility for the person's day- to- day care.
It may arise out of individual cruelty, inadequate service provision or society's indifference.
It requires a proportional response,- one which does not cut across valid choices made by individuals with disabilities but one which does recognise vulnerability and exploitation.

All of these issues affect people using mental health services whose vulnerability is often hidden behind exaggerated public concerns and stereotypes about mental illness leading to dangerousness rather than very often arising out of and leading to vulnerability.

In the working group we formulated a "social" model of vulnerability that parallels the social model of disability with its focus on society's response to differentness rather than the initial impairment as the root of social exclusion and discrimination. Vulnerability can also be understood as a result of cumulative layers of disadvantage. "The Protection agenda" starts out looking as if it is a patronising and paternalistic stance in response to people who are inherently "weaker" than other people but when examined more closely we see that disabled people from all client groups, are exposed to risks which other citizens would find unthinkable, they are then treated less favourably if they report crimes or abuses of their rights and finally they receive far less support and opportunity for redress than other citizens. For example a woman or man who is depressed may be admitted to an open mixed sex ward where they are expected to share their living space with people they do not know and who may be violent or irresponsible; if they report concerns or instances of personal violence they may be disregarded, disbelieved or the matter may either be dismissed because it is the norm, or swept under the carpet in order to protect the institution from public scrutiny. The police will not help a person assaulted in such a setting to prosecute their assailant, and nor is it likely that they will receive compensation or counselling to overcome any trauma. Citizens who are not labelled or in receipt of social care services would not expect to be treated in this way if they are victims of violence.

For people with mental health problems there are additional concerns arising out of the sometimes-legitimate breaches of human rights in relation to detention, public safety, mental incapacity and compulsory treatment. Member states have their own legal systems to address these arenas but the report spells out very clearly the need for any decisions which have the potential to cut across human rights, particularly in relation to irreversible or end-of-life decisions, involvement in research or use of contested treatments which persist without sound evidence of effectiveness, ---that these should be made transparently, scrutinised independently and with rights to appeal. Legal changes to allow compulsory treatment in the community and to shift the balance towards public protection by detaining people, who are deemed to be at risk of offending in advance of their actually being convicted under due process, are currently the subject of much debate in the UK.

The group documented examples of good practice in terms of a matrix showing the stage and level of intervention. Primary prevention of abuse requires strong adherence to human rights, interventions to help individuals to know these rights and assert their needs, proper recruitment and training to prevent unsuitable staff from coming into contact with people when they are vulnerable and also to equip them with the knowledge they need to respond humanely to people even when they are challenging; good laws to limit abuses to human rights and public acceptance and understanding. If despite these measures abuses do take place then arrangements must be agreed between agencies for secondary prevention, in that abuse is promptly recognised, investigated and acted upon. Lastly tertiary prevention is designed to ameliorate any harm done and help people to recover their equilibrium, confidence and trust in others.

These layers of anticipation and response to abuse are of especial importance in mental health services given the wealth of evidence linking mental ill health to prior as well as current abuse. Adult survivors of childhood abuse are particularly likely to come into mental health services, and it is therefore of particular importance that they find there a safe place in which their experiences are acknowledged and made sense of. Women with mental health problems also present with heightened risks of current domestic violence and when people with mental health problems resume their lives in the community they encounter stigma and discrimination. Services need to be alert to family violence and its long-term effects just as families need to be alert to the myriad ways in which services can impinge on the rights and integrity of people struggling with mental illness or distress.

Conclusion

The report makes visible a broad range of harm and mistreatment, which occurs across a range of settings and circumstances. It advocated a complex model of protection that enhances the rights of disadvantaged groups and acknowledged the extent to which they are at additional risk of violence and abuse, while receiving less favourable treatment if they are victims of crime. The group’s recommendations provided an achievable agenda for action at all levels against which progress can be measured.

At a day held in December 2001 disabled activists, including survivors of mental health systems across Europe, met to discuss prevention of abuse, and made it very clear that whilst statutory agencies might be in a position to champion the rights of some groups, the balance was tipped towards mental health service users requiring safeguards which were located outside and independently of service provision. They located the major risks as arising out of service settings, legal instruments to detain them and compulsory treatment. Taken together this with everyday personal violence and abuse this is a complicated agenda for service users and providers. It is not an agenda governments can sidestep, or put aside while they attend to more populist measures around public safety, because people who use mental health services are the public too… and as such governments have a responsibility to ensure that the risks they run are counterbalanced by proper safeguards in law and in practice.

Work to protect all children and adults with disabilities in our communities, and especially those with mental health problems, should be seen as an important and integral part of the Council of Europe’s broader commitment to integration and social inclusion.

FOURTH SESSION

Equality, non-discrimination and social justice: employment, education, health care, social security

QUATRIEME SESSION

Egalité, non-discrimination et justice sociale : emploi, éducation, soins médicaux, sécurité sociale

PROTECTING THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES: THE EUROPEAN CONVENTION ON HUMAN RIGHTS

Oliver LEWIS[52]
Legal Director, Mentality Disability Advodacy Centre,
Budapest

The European Convention on Human Rights ("the Convention") was born in 1950 of the new Council of Europe.[53] The aim of the Convention and the European Court of Human Right ("the Court") - set up to decide individual cases and located in Strasbourg, France - was to protect individuals in Europe from atrocities such as those committed during the Nazi regime. Although developments of psycho-pharmaceutical therapy and various talking therapies were made in the twentieth century, the same century participated in the torture and murder of thousands of children and adults with mental health problems and developmental disabilities.[54]

The Convention and the case law of the Court are not only reference points by which governments can enact laws and national courts can interpret laws. More substantially, the Convention acts as an international check on government excesses, or as commonly in the mental disability field, neglect. Its massive geographical remit, which has expanded vastly since the collapse of communist states during 1989 and 1990, now stretches 44 countries from the Arctic Circle down to the Mediterranean coast, to the borders of Syria, Kazakhstan and China. The Convention is the largest and most developed regional human rights protection mechanism in the world. All European Union ("EU") Member States have signed and ratified the Convention, as well as the EU accession countries, and many others.

The protection of human rights for people with mental disabilities[55] (mental illness and/or intellectual disabilities) is more than of marginal importance for democratic societies. Violations of human rights can have a detrimental affect on mental health (people who suffer racism, for example, are at increased risk of developing mental health problems, or worsening of existing conditions);[56] and – as this paper will discuss - the way mental health services are structured and delivered may violate human rights. Therefore promoting mental health and human rights are complementary and mutually reinforcing.[57]

---

[52] Oliver Lewis, LLB, MA, of the Bar of England and Wales and door tenant of Coram Chambers London, is legal director of the Mental Disability Advocacy Center, Budapest. Address for correspondence: MDAC, Budapest 1051, Október 6. u. 12, Hungary. oliver@mdac.info A shortened version of this paper was originally presented in April 2002 at an international workshop on health care and human rights organised by the Hungarian Civil Liberties Union. My thanks go to Peter Bartlett, Jill Peay, Eva Szeli and Oliver Thorold for their helpful comments on an earlier draft. Any errors, of course, remain mine.

[53] Its full title is the "European Convention on Human Rights and Fundamental Freedoms", signed in Rome on 4 November 1950

[54] Mainly under the covert Nazi bureaucracy T-4 "…whose task it was to organise the registration, selection, transfer and murder of a previously calculated target group of 70,000 people, including schizophrenics, epileptics and long-stay patients" from 1997, M. Burleigh, *Ethics and Extermination* (Cambridge, CUP, 1997), p.123

[55] The term "mental disability" is used throughout this paper. Other documents, notably those produced by the World Health Organisation, use the term "mental disorder"

[56] World Health Organisation, *World Health Report 2001 Mental Health: New Understanding, New Hope* (Geneva: WHO, 2001), p.15

[57] Mann, J. M., Goston, G., Gruskin, S. et al "Health and Human Rights", *Journal of Health and Human Rights.* No. 7 (1994)

The Convention is now over 50 years old, but its mental disability case law is still somewhat underdeveloped, as this paper will explore. The Court has only begun to tackle – notably in the case of Varbanov v. Bulgaria[58] - the complex legal frameworks governing mental disability law in central and eastern European countries.

The Convention is an international treaty which is binding on all those countries which have ratified it. The rights set forth in the Convention and case law of the Court are not "soft" guidelines, recommendations or suggestions but "hard" law which is directly enforceable in domestic courts. Ratification of the Convention brings with it a promise by a State to "secure to everyone within their jurisdiction the rights and freedoms defined in [the Convention]".[59] If a domestic court cannot or does not uphold Convention rights, the victim may, after exhausting national remedies, turn to the European Court of Human Rights. Each case decided by the Court is applicable not only in the defendant country, but all of the countries which have ratified the Convention. For the majority of countries within the Council of Europe, signing up to the Convention forces code-based civil law legal systems to incorporate a case-law body of international law.

This paper will analyse the essential legal requirements of the European Convention on Human Rights which touch on the lives (and deaths) of people with mental disabilities. It will examine the procedural safeguards which must be followed when involuntary detaining a person under mental health legislation; access to a court to test the lawfulness of detention; the requirement to be free from torture, inhuman or degrading treatment or punishment; the right to respect for private and family life, home and correspondence; and the right to life, including investigation after a death. The paper will discuss some of the factors which explain the relative scarcity of mental disability cases decided by the Strasbourg Court. In conclusion there will be an examination of the role of lawyers and other key players in mental disability, and how stakeholders can move forward to prompt much needed social reform.

Detention, review, and discharge

The jurisprudence of the European Court of Human Rights of the procedural requirements of psychiatric detention, review and discharge (Article 5) has since 1979 built on the terms of the Article to create a number of clear requirements.

Article 5 of the European Convention on Human Rights states:

5(1) Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(a) the lawful detention of a person after conviction by a competent court;

[…]

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;

[…]

5(2) Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him.

[…]

---

[58] Varbanov v. Bulgaria Application No. 31365/96, judgment 5 October 2000

[59] Article 1, European Convention on Human Rights

5(4) Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

5(5) Everyone who has been the victim of arrest or detention in contravention of the provisions of this article shall have an enforceable right to compensation.

Article 5 provides for liberty, but allows detention for a number of grounds, one of which is for "persons of unsound mind". This now outdated and stigmatising term legitimises in international law the power of a State to involuntarily detain people with mental disabilities in a psychiatric institution. Article 5 regulates entry into and discharge from institutional facilities. Article 5 does not touch on what happens *inside* an institution: a topic to which we shall return later.

In Winterwerp v. Netherlands[60], the first mental disability case to reach the Strasbourg Court, three relatively undemanding requirements for a valid detention of "persons of unsound mind" were laid out in the judgement. The Court stated:

> "In the Court's opinion, except in emergency cases, the individual concerned should not be deprived of his liberty unless he has been reliably shown to be of 'unsound mind'. The very nature of what has to be established before the competent national authority – that is, a true mental disorder – calls for objective medical expertise. Further, the mental disorder must be of a kind or degree warranting compulsory confinement. What is more, the validity of continued confinement depends upon the persistence of such a disorder". [61]

In Varbanov v. Bulgaria,[62] the applicant's detention had been decided upon by a prosecutor without a medical assessment. Unsurprisingly, the Strasbourg Court emphasized that a psychiatric detention must be medically indicated.

The requirement that the deprivation of liberty should be "in accordance with a procedure prescribed by law", was explained in Winterwerp as meaning that the State authorities must comply with domestic legislation, and domestic legislation must itself be compatible with the Convention, with its notion of a "fair and proper procedure". Effectively it therefore requires that the procedure be codified. In the recent case of Kawka v Poland[63] the Court stressed that:

> "where deprivation of liberty is concerned, it is particularly important that the general principle of legal certainty is satisfied. It is therefore essential that the conditions for deprivation of liberty under domestic law should be clearly defined, and that the law itself be foreseeable in its application, so that it meets the standard of "lawfulness" set by the Convention, a standard which requires that all law should be sufficiently precise to allow the person – if needed, to obtain the appropriate advice – to foresee, to a degree that is reasonable in the circumstances, the consequences which a given action may entail."[64]

Although the powers under which State authorities purport to psychiatrically detain someone must be codified, States enjoy some discretion in deciding what qualifies as "unsoundness of mind", in other words, which mental disabilities should be included in mental disability legislation, and which should be excluded. The Court in Winterwerp was unwilling to define what is essentially a medical question

---

[60] Winterwerp v. the Netherlands Application No. 6301/73, judgment 24 October 1979, reported at 2 EHRR 387
[61] Winterwerp v. the Netherlands, *op cit*, paragraph 39
[62] *op cit*
[63] Kawka v. Poland Application No. 25874/94, judgment 9 January 2001
[64] Kawka v. Poland, *op cit*, paragraph 49

apparently best answered by national authorities guided by scientific expertise. It is surprising that the Court has not laid down any substantive guidelines other than "kind or degree" concerning how severe or dangerous a person's mental disability needs to be to trigger compulsory detention. Compare the United States jurisprudence. In the 1972 landmark case of Lessard v. Schmidt the Supreme Court ruled that when doctors decide that a person is of sufficient "dangerousness" to warrant compulsory confinement, that opinion must be "based upon a finding of a recent overt act, attempt or threat to do substantial hard to oneself or another."[65]

More directly relevant to countries which have ratified the European Convention on Human Rights is Principle 16 of the United Nations "Principles for the Protection of Persons with Mental Illness" (1991)[66] which specifies that a person may only be admitted involuntarily as a psychiatric patient if a medical practitioner is of the opinion that s/he has a mental illness, "and considers

> (a) That, because of that mental illness, there is a serious likelihood of immediate or imminent harm to that person or to other persons; or
>
> (b) That, in the case of a person whose mental illness is severe and whose judgement is impaired, failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative."

Although the UN Principles are not legally binding on any country, they do represent a set of international "soft law" standards which protect and promote the rights of people with a mental disability. It would be difficult for the Strasbourg Court to ignore the UN Principles. Indeed, so-called "soft law" is used by courts as an interpretive guideline to binding law, and may be used by lawyers to assist in their submissions.

Unlike the UN Principles,[67] Article 5 of the European Convention on Human Rights does not create a right to treatment,[68] nor a right to hospital care suitable for the patient.[69] However, detention of a person on grounds of "unsound mind" will only be lawful for the purposes of Article 5(1)(e) if the detention takes place in a hospital, clinic or other appropriate therapeutic institution. A prison is not an acceptable facility for civil psychiatric detention nor for those who have been found not to be responsible for a criminal offence.[70]

Delay between examination and report

Winterwerp mandates that psychiatric detention must be medically indicated. If the doctor's decision is based on medical information which did not necessarily reflect the applicant's condition at the time of the decision, the "delay between clinical examination and preparation of a medical report is in itself capable of running counter to the principle underlying Article 5 of the Convention, namely the protection of individuals against arbitrariness as regards any measure depriving them of their liberty."[71] In Varbanov v Bulgaria, the Court emphasised that the medical assessment of the individual must be based on the actual mental state of the person rather than solely on past events.[72]

---

[65] Lessard, 349 F. Supp at 1082

[66] Adopted by the UN General Assembly resolution 46/119 of 17 December 1991

[67] Guaranteed by Principle 8 of the UN Principles

[68] See Winterwerp v. the Netherlands, *op cit*, paragraph 51

[69] Ashingdane v. the United Kingdom Application No. 8225/78, judgment 28 May 1985, reported at (1985) 7 EHRR 528

[70] Aerts v. Belgium Application No. 25357/94, judgment 30 July 1998, reported at (1998) 29 EHRR 50

[71] Musial v. Poland, Application No. 24557/94, judgement 25 March 1999 paragraph 50

[72] *op cit*

Giving reasons

The Strasbourg Court has held that Article 5(2) – the obligation to give reasons for detention - applies to mental health detention as well as criminal detention,[73] but the Court has not decided whether the information given at the time of detention need be in written form. In the future the Court may well expand its case law and require written information when a person is detained. Firstly, on admission a patient may be suffering from an acute mental heath crisis (or at the least, be anxious), and therefore when he/she is being detained may not have the capacity to understand the reasons for detention. Secondly, a patient may subsequently wish to mount a legal challenge to the detention. This is possible only if the patient knows the basis upon which s/he is detained.

Challenging lawfulness of detention

This legal challenge, provided for in Article 5(4), is the most far-reaching of the rights in Article 5. An independent Court review, whereby the lawfulness of detention is decided speedily is the essential check on psychiatry's unusual power to detain people against their will.

Article 5(4) may be satisfied in one of two ways: either by giving the patient a right to apply to a court at a time of his choosing, or by automatic periodic review. The Strasbourg Court has addressed the following issues: powers of the reviewing court; judicial character; frequency of the periodic review; speed between application and review; and legal representation.

In Winterwerp v. Netherlands the Strasbourg Court laid down the essential requirements of a court hearing under Article 5(4):

> "The judicial proceedings referred to in Article 5(4) need not, it is true, always be attended by the same guarantees as those required under Article 6(1) for civil or criminal litigation. Nonetheless, it is essential that the person concerned should have access to a court and the opportunity to be heard either in person or, where necessary, through some form of representation, failing which he will not have been afforded the 'fundamental guarantees of procedure applied in matters of deprivation of liberty'. Mental illness may entail restricting or modifying the manner of exercise of such a right, but it cannot justify impairing the very essence of the right. Indeed special procedural safeguards may prove called for in order to protect the interests of persons who, on account of their mental disabilities, are not fully capable of acting for themselves." [74]

In cases since the Winterwerp[75] decision the Strasbourg Court has explained that a "court" in this context need not have the full guarantees of a criminal court, but must have "independence of the executive and of the parties to the case, but also the guarantees ('appropriate to the kind of deprivation of liberty in question') of [a] judicial procedure."[76]

One of the guarantees of a judicial procedure is the notion of "equality of arms", or due process. In Nikolova v. Bulgaria the Court stated that "Equality of arms is not ensured if counsel is denied access to those documents in the investigation file which are essential effectively to challenge the lawfulness

---

[73] Van der Leer v. the Netherlands Application No. 11509/85, judgment 21 February 1990, reported at (1990) 12 EHRR 567

[74] *op cit*, paragraph 60

[75] See X v. the United Kingdom Application No. 7215/75, Series A, No.46, judgment 24 October 1981, reported at (1981) 4 EHRR 188, Wassink v Netherlands Series A no. 185-A, judgment 27 September 1990

[76] On independence of the reviewing court see DN v. Switzerland Application No. 27154/95, judgment 29 March 2001, commentary at (2001) 5 EHRLR 589

of his client's detention."[77] It is vital that the patient is given materials which contain the information upon which he can challenge the evidence against him. There may be factual inaccuracies on which the decision to detain has been made. There may be issues about the psychiatric diagnosis, or the risk assessment which the patient may wish to challenge by way of cross-examination or by introducing counter-evidence. It is important that psychiatrists substantiate their medical opinions rather than merely asserting conclusions. Therefore the patient's medical, nursing and social file must be shared with the patient and the legal representative. It follows (although the Court has not yet had the opportunity to rule on this point) that the patient must be given a reasonable opportunity to photocopy and read relevant sections of the files and that the cost of this is borne by the State.

Frequency and speed of reviews

The Strasbourg Court has not yet stated definitively how frequently a patient must be able to exercise his 'periodic' right to review detention under Article 5(4). In E v. Norway[78] the Strasbourg Court held that a period of 55 days (seven weeks and six days) between an application for review and a decision by a court was insufficiently speedy. The maximum permissible time remains undecided, but could be held to be as little as four or six weeks. Although in some countries it appears to be an administrative burden on the State to fix a hearing so quickly, from the detained person's perspective eight weeks is a long time to be detained without independent review.[79] In many jurisdictions psychiatric detention invariably includes treatment with powerful and sometimes harmful psychotropic medication. In other jurisdictions review hearings occur more quickly than the limits set thus far by the Strasbourg Court. For example, in Ontario, Canada, legislation allows for a patient to apply for a court review in the first 72 hours of detention, then after two weeks, again the next month, again during the next two months, and again during the next three months of detention. Hearings must take place no later than one week after application, with a decision within 24 hours of the hearing, and reasons (if requested) no later than 48 hours after the request.[80]

In a logical progression, the Strasbourg Court held in Musial v. Poland that "Article 5(4), in guaranteeing to persons arrested or detained a right to institute proceedings to challenge the lawfulness of their detention, also proclaims their right, following the institution of such proceedings, to a speedy judicial decision concerning the lawfulness of detention and ordering its termination if it proves unlawful."[81] In Musial the time between application for a review and the decision by the court was one year, eight months and eight days. The Court held that such a length of time would clearly be in breach of Article 5(4) unless the government had exceptional grounds to justify it - which in Musial it did not.

---

[77] Nikolova v. Bulgaria Application No. 31195/96, judgment 25 March 1999, reported at (2001) 31 EHRR 3, paragraph 58

[78] E. v. Norway Application No. 11701/85, judgment 29 August 1990, reported at (1990) 17 EHRR 30

[79] In England and Wales, see, for example, The Queen on the Applications of KB, MK, JR, GM, LB, PD and TB v. The Mental Health Review Tribunal and the Secretary of State for Health, in the Administrative Court [2002] EWHC 639 (Admin.)

[80] Section 20 of the Ontario Mental Health Act 1978

[81] Musial v. Poland *op cit*, paragraph 43

Legal representation

A fundamental guarantee for a patient at Article 5(4) review hearings is that the s/he should be legally represented. In Megyeri v. Germany[82] the European Court of Human Rights found a violation of Article 5(4) because the applicant did not receive legal representation at his Article 5(4) hearing. The Strasbourg Court explained,

> "… that where a person is confined in a psychiatric institution on the ground of the commission of acts which constituted criminal offences but for which he could not be held responsible on account of mental illness, he should – unless there are special circumstances – receive legal assistance in subsequent proceedings relating to the continuation, suspension, or termination of his detention. The importance of what is at stake for him – personal liberty – taken together with the very nature of the affliction – diminished mental capacity – compels this conclusion."[83]

It cannot yet be assumed that legal representation is a right for all detained patients. Mr Megyeri's mental disability appears to have been relatively severe at the relevant time. A *criminal* court had decided that he could not be held responsible for his acts because he was suffering from paranoid schizophrenia, and at the time of the hearing his mental state was said to have deteriorated. Even if a right to representation funded by the State is not yet a general right, a court which reviews detention must always consider whether a particular person is capable of acting for himself, for example, whether he is able to marshal arguments and points in his favour, and understand any legal issues arising. If not, then legal representation must be provided and must be paid for by the State.

Two arguments can be made to advance the jurisprudence so that all detained patients are entitled to legal representation at reviews concerning their continued detention. Firstly, according to the Court in Megyeri, where (1) the person's liberty is in question, and (2) the person has a diminished mental capacity, he should receive legal representation at hearings concerning his continued detention. These two criteria apply equally to civilly detained patients as they do to patients who have been detained via the criminal route.

Secondly, in analogous cases where the issue is continued detention, the Court has examined the criminal law procedure followed in England and Wales of a "parole board" reviewing whether a prisoner should be released after a term of imprisonment. Where continued detention may be at stake, and where it is necessary to examine dangerousness, the person's character or maturity, or his mental state, the Court has required "… an oral hearing in the context of an adversarial procedure involving legal representation and the possibility of calling and questioning witnesses."[84] If prisoners facing continued detention are entitled to legal representation, it follows logically that those people detained for psychiatric reasons (who may be suffering from mind clouding side effects of medication or a mental disability) must be entitled legal representation.

Around the world it is common that lawyers assigned mental disability detention cases do not perform adequately. Perlin and Dorfman writing in the United States describe lawyers who are assigned mental disability cases in many jurisdictions as "woefully inadequate – disinterested, uninformed, role-less and often hostile".[85] They further point out that lawyers in such cases often substitute a traditional legal advocacy model for a "paternalism/best interests" model. Mental disability law remains of marginal interest for most lawyers also within the European Convention region.

---

[82] Megyeri v. Germany Application No. 13770/88, judgment 12 May 1992, reported at (1992) 15 EHRR 584

[83] Megyeri v. Germany, *op cit*, paragraph 23

[84] See Singh v the United Kingdom Application No. 23389/94, judgment 26 January 1996 (paragraph 68) and Hussain v the United Kingdom, Application No. 21928/93, judgment 26 January 1996 (paragraph 60)

[85] M.L. Perlin and D.A. Dorfman, "Is it more than 'dodging lions and wastin' time?' Adequacy of counsel, questions of competence and the judicial process in individual right to refuse cases" (March 1996) *Psychology, Public Policy and Law*

The European Court of Human Rights has only recently begun to adjudicate on adequacy of legal representation. In the case of Pereira v. Portugal,[86] the applicant suffered from a mental disability that prevented him from conducting court proceedings satisfactorily, despite his legal training. The circumstances of the case therefore dictated the appointment of a lawyer to assist him in the proceedings concerning the periodic review of the lawfulness of his confinement. A judge had assigned a lawyer at the outset of the proceedings but the lawyer had played no role in the proceedings. The Court found a violation of Article 5(4) - merely appointing counsel does not ensure that the client will receive effective legal assistance. Countries within the Council of Europe are therefore obliged to monitor the adequacy of legal assistance given to patients and to provide mechanisms for inadequacies to be addressed and remedied.

In future cases the European Court of Human Rights may go further than this and answer the question of what constitutes *adequate* or *effective* legal services? Recently in the American case of In re Mental Health of K.G.F. the Supreme Court of Montana gave an extraordinarily detailed judgment fleshing out statutory provisions and providing guidance on counsel's duties in civil commitment proceedings.[87] The Court was asked "*how* effective counsel must be when representing an individual who is facing an involuntary commitment".[88] The Montana court found that the standard of "reasonable professional assistance" was too low. It said that counsel should have undergone specialized training of mental disability law, as well as alternative, less-restrictive treatment and care options. Before a hearing, counsel should go through with the client the medical history, family relations, as well as discussing practical and legal consequences of all available options. The initial interview with the client should be held sufficiently before any court hearings to allow for effective preparation. Counsel should explain the legal process and the client's rights and (crucially) "should also ascertain, if possible, a clear understanding of what the client would like to see happen in the forthcoming commitment proceedings".[89] Counsel should then interview everyone who has knowledge of the circumstances surrounding the initial detention, and to consider calling these people as witnesses. A patient has the right for counsel be present during a psychiatric examination conducted for the purposes of the court proceedings – indeed it would be a "patent due process violation for the 'examination' to be conducted … without the assistance of counsel..."[90] The Montana Court also confirmed that counsel should not adopt a paternalistic / best interests approach to advocacy. Agreeing with the guidelines brought to the Court's attention,[91] the Court confirmed that"[w]hen an attorney fails to act as an advocate and assumes a paternalistic or passive stance, the balance of the system is upset, the defence attorney usurps the judicial role, and the defendant's position goes unheard."[92]

The Strasbourg Court has emphasised that "its task is not to rule on legislation *in abstracto* and it does not therefore express a view as to the general compatibility of […] provisions and practice with the Convention".[93] For general guidance therefore, governments and domestic judges who insist that a State's obligation ends when a lawyer is assigned to represent a person with mental disability should perhaps look across the Atlantic for insightful appellate court reasoning, and to predict the reasoning which the Strasbourg Court may adopt in future cases.

---

[86] Pereira v. Portugal Application No.44872/98, judgment 26 February 2002
[87] 29 P.3d 485 Mont. 2001. Decided 2 August 2001.
[88] In re Mental Health of K.G.F. *op cit*, paragraph 32
[89] In re Mental Health of K.G.F. *op cit*, paragraph 79
[90] In re Mental Health of K.G.F. *op cit*, paragraph 83
[91] National Center for State Courts' Guidelines for Involuntary Civil Commitment. *See* 10 Mental and Physical Disability Law Reporter, 409--514 (No. 5-1986)
[92] In re Mental Health of K.G.F. *op cit*, paragraph 85
[93] Nikolova v. Bulgaria Application No. 31195/96, judgment 25 March 1999, reported at (2001) 31 EHRR 3, paragraph 60

The author observed a series of Article 5(4) cases in Hungary in 2002. These were the annual court reviews of patients who had been sent to a high security hospital following a criminal court's finding of not responsible due to mental disability. Some cases lasted less than 2 minutes. The court-appointed lawyer never met the client before or after the hearing. Representations (if any) were made without instructions using a "best interests" advocacy model. The lawyer did not know the content of psychiatric reports. Although on paper it may be claimed that the patient's rights are respected by the appointment and appearance of a legal representative, in reality the lawyer was purely cosmetic and added nothing to the court procedure. This situation is replicated across central and eastern Europe: States are leaving themselves wide open to challenge at Strasbourg.

Right to compensation for Article 5 violations

The right to compensation set out in Article 5(5) is a right enforceable by a national court, leading to a legally binding award. Article 5 is the only Article in the Convention which specifies compensation, thereby indicating the seriousness with which the authors of the Convention viewed unjustified detention. A violation of any aspect of Article 5 attracts a right to compensation. The Court has made it clear that a remedy before some body other than a court (e.g. an ombudsman), or an *ex gratia* award, is not sufficient to satisfy the requirements of Article 5(5).[94]

Care and treatment within psychiatric institutions

Article 3, the shortest article in the Convention, reads: "*No one shall be subjected to torture or to inhuman or degrading treatment or punishment.*" The prohibition is absolute. The Court has emphasised that such a fundamental right deserves no exceptions or limitations. Nor can States derogate from Article 3, which imposes a negative obligation on the Sate not to inflict torture, inhuman or degrading treatment or punishment on people. It also creates a positive obligation on States to take measures to protect people from suffering Article 3 abuses – whether carried out by State officials or private individuals or groups.

In various cases the European Court of Human Rights has developed definitions of the key terms.[95] *Torture* has come to mean the deliberate inhuman treatment causing very serious and cruel suffering. *Inhuman treatment or punishment* is intense physical or mental suffering, whilst *degrading treatment or punishment* arouses in the victim feelings of fear, anguish and inferiority capable of humiliation and debasement and possibly breaking physical or moral resistance. However, not every unpleasant act falls within the ambit of Article 3. Ill-treatment must attain a *minimum level of severity* to fall within the scope of Article 3. The assessment of this standard is relative; it depends on all the circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim.[96]

In Kudla v. Poland[97] the Court said that inhuman or degrading treatment must "go beyond that inevitable element of suffering or humiliation connected with a given form of legitimate treatment or punishment" to be deemed a violation of Article 3. The question is, what is a "legitimate" form of treatment or punishment?

---

[94] Brogan v. the United Kingdom Application No. 11209/84, judgment 29 November 1988, reported at (1988) 11 EHRR 117

[95] See for example, Ireland v. the United Kingdom Series A no. 25, judgment 18 January 1978, pages 65--67, paragraph 162

[96] Tekin v. Turkey Application No. 22496/93, judgment 9 June 1998 (paragraph 108)

[97] Kudla v. Poland Application No. 30210/96, judgment 26/10/00, reported at (2002) 35 EHRR 11

There have been very few cases brough to the Strasbourg Court which have tested the extent to which features of the psychiatric care system may be violative of Article 3. Perhaps the most famous of the handful is Herczegfalvy v. Austria,[98] a case in which the Court did not take a particularly progressive stance on the issue of physical restraints. Mr Herczegfalvy was forcibly administered food and neuroleptic medication, isolated and attached with handcuffs to a security bed for some weeks. He complained about his treatment was violent and excessively prolonged, and taken together had amounted to inhuman and degrading treatment, and even contributed to the worsening of his condition.

The Austrian government responded by arguing that his treatment was essentially the consequence of Mr Herczegfalvy's behaviour, as he had refused medical treatment which was urgent in view of the deterioration in his physical and mental health. The government explained that his "resistance to all treatment, his extreme aggressiveness and the threats and acts of violence on his part against the hospital staff which explained why the staff had used coercive measures including the intramuscular injection of sedatives and the use of handcuffs and the security bed. These measures had been agreed to by Mr. Herczegfalvy's curator [guardian], their sole aim had always been therapeutic, and they had been terminated as soon as the state of the patient permitted this."[99] The Court therefore found no violation of Article 3.

It is noteworthy that the Court heard this case in 1992, and Mr Herczegfalvy complained of treatment which took place between 1978 and 1984. As the Convention is a "living instrument"[100] it is quite possible that today's differently constituted Court would come to a different conclusion.

Despite the decision in Herczegfalvy, in its judgment the Court stated that increased vigilance is required by the Court because of the vulnerability of people with mental health problems. It went on to say that if medical experts assess a measure to be a "therapeutic necessity", the Court is unlikely to find a violation of Article 3. The Court must nevertheless satisfy itself that the medical necessity has been convincingly shown to exist. In other words, medical opinion can be challenged, and the Court may disagree with the doctors:

> The Court considers that the position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with. While it is for the medical authorities to decide, on the basis of the recognised rules of medical science, on the therapeutic methods to be used, if necessary by force, to preserve the physical and mental health of patients who are entirely incapable of deciding for themselves and for whom they are therefore responsible, such patients nevertheless remain under the protection of Article 3, the requirements of which permit of no derogation. The established principles of medicine are admittedly in principle decisive in such cases; as a general rule, a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading. The Court must nevertheless satisfy itself that the medical necessity has been convincingly shown to exist. [101]

The highly deferential "therapeutic necessity" test limits the Strasbourg Court's ability to enquire into the quality of treatment, and it encourages national courts to accept institutional decision making.[102]

---

[98] Herczegfalvy v. Austria Application No. 10533/83, judgment 24 September 1992, reported at (1992) 15 EHRR 437

[99] Herczegfalvy v. Austria *op cit*, paragraph 81

[100] Tyrer v. United Kingdom, Application No. *5856/72*, judgment 25 April 1978, reported at (1978) 2 EHRR 1 (paragraph 31)

[101] Winterwerp v. the Netherlands *op cit*, paragraph 80

[102] For an American perspective on this point, see M. Perlin., *The Hidden Prejudice: Mental Disability on Trial* (American Psychological Association, 2000), page 122

The high standard of proof coupled with the doctrine of therapeutic necessity go some way to explaining why there have been so few challenges under Article 3 involving psychiatric care.

There is first-hand evidence particularly in central and Eastern Europe and the former Soviet States of treatment which has been approved by a doctor (and would therefore be argued to be of "therapeutic necessity") but which arguably does violate Article 3. Such practices include electroconvulsive therapy without anaesthesia or muscle relaxants ("unmodified ECT");[103] and the use of caged-beds[104] for prolonged periods,[105] both of which have been condemned by intergovernmental organisations.[106] The Court may find that these barbaric practices - where it is difficult objectively to find a therapeutic or ethical motive - amount to torture.

Article 3 therefore can be used to challenge practices which some may regard as acts beyond the scope of modern humane psychiatric treatment. The Article can also be used to challenge inadequate psychiatric supervision of a patient or prisoner.

In the case of Keenan v. the United Kingdom,[107] Mark Keenan, a young man with a known history of mental illness who was serving a prison sentence, was given a serious disciplinary punishment of seven days segregation in a punishment block and an additional 28 days on his sentence. During segregation he was ineffectively monitored and there was no informed psychiatric input into his assessment and treatment. The Court found that such punishment, which may have threatened his physical and moral resistance, in these circumstances was "not compatible with the standard of treatment required in respect of a mentally ill person"[108] and therefore violated Article 3. Tragically, Mark Keenan took his life whilst in segregation, and the case was brought to Strasbourg by his parents.

---

[103] See Bulgarian Helsinki Committee *Inpatient psychiatric care in Bulgaria and human rights* (Sofia, Bulgarian Helsinki Committee, 2001), which reports that unmodified ECT is still carried out in at least 8 facilities in Bulgaria. The report also quotes a survey by the Bulgarian Psychiatric Association which revealed that nearly 20% of psychiatrists polled prescribe ECT without anaesthesia or muscle relaxants

[104] The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) described a caged-bed: "The bed measured 2.08 m x 0.93 m, and was covered with a strong net, fixed on a tubular metal structure 1.26 m in height, an articulated opening with a padlock having been made on the left-side." Paragraph 56 of CPT report on the visit to Hungary of 1999, published 29 March 2001, reference CPT/Inf (2001) 2. The report from Mental Disability Rights International *Mental Disability and Human Rights: Hungary* (1997) also describes caged beds: "The cages observed in Hungary are uniform in construction. They consist of metal frames built approximately 2 to 3 feet over a bed with a wire or net mesh enclosing all sides and the top. The cage permits a person to roll over or sit up but not stand up. The side of the cage can slide open or can be shut with a padlock."

[105] See G. Gombos, E. Kismõdi, K. Petõ, *The human rights of patients in social care homes for the mentally ill* (Budapest, Hungarian Mental Health Interest Forum, September 2001). The authors monitored all 52 psychiatric long-stay "social care homes" in Hungary (total population approximately 6400) and found that caged-beds were in use in 8 homes. In one home there were 12 caged-beds

[106] On "unmodified" electro-convulsive therapy, see the Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) "Substantive Sections" paragraph 39 [CPT/Inf (98) 12] which states that "this method can no longer be considered as acceptable in modern psychiatric practice. Apart from the risk of fractures and other untoward medical consequences, the process as such is degrading for both the patients and the staff concerned."

For criticisms of caged-beds, see the CPT's 1999 report on Hungary, published March 2001 [CPT/Inf (2001) 2] in which the CPT made immediate observations and demanded that "all caged beds should be immediately withdrawn from service in psychiatric institutions throughout Hungary; they can no longer be considered as acceptable in modern psychiatric practice" (para 8)

[107] Keenan v. the United Kingdom Application No. 27229/95, judgment 3 April 2001, reported at (2001) 33 EHRR 38

[108] Keenan v. the United Kingdom *op cit*, paragraph 115

As well as mistreatment and lack of supervision, "conditions of detention may sometimes amount to inhuman or degrading treatment".[109] A recent case concerning physical disability reveals the non-discriminatory approach of the Strasbourg Court when assessing the possible special requirements of people with a (mental or physical) disability.

Price v. the United Kingdom[110] concerned a woman who was a wheelchair user and did not have the use of any of her limbs. She was sent to prison for one week and alleged that whilst in custody she was forced to sleep in her wheelchair, she could not reach the emergency buttons and light switches, and that she was unable to use the toilet. She alleged that she was lifted onto a toilet by a female prison officer but was then left sitting on the toilet for over three hours until she agreed to allow a male nursing officer to clean her and help her off the toilet. Ms Price alleged a violation of Article 3.

The European Court of Human Rights confirmed that the absence of any intention to humiliate or debase cannot conclusively rule out a finding of violation of Article 3. Ms Price suffered because the conditions were not appropriate for someone with such a disability. The Court's assessment of the minimum level of severity depends on the circumstances of the case, including the duration of the treatment, its physical and mental effects and, in some cases, the sex, age and (crucially) the state of health of the victim. In this case "to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to Article 3".[111] In another prison case, the Court found that being kept in a prison cell, mostly confined to a bed, as well as having to use the toilet in the presence of others amounted to degrading treatment within the meaning of Article 3.[112] When assessing conditions of detention, the Court will take account of the *cumulative* effects of conditions (such as overcrowding, inadequate facilities for heating, sleeping arrangements, food, recreation, toilets, washing, contacts with the outside world).[113]

As yet, there has been no successful Article 3 case at Strasbourg on the conditions within a mental disability hospital or home. Most probably, the majority of future cases brought by people with mental health problems or developmental disabilities in which an Article 3 breach is alleged, will involve a finding of inhuman and degrading treatment, not torture. However, the Court has hinted that acts currently classified as inhuman and degrading treatment "could be classified differently in the future".[114] The Court has said that "the increasingly high standard being required in the area of the protection of human rights and fundamental liberties correspondingly and inevitably requires greater firmness in assessing breaches of the fundamental values of democratic societies".[115]

The standard of proof in Article 3 cases is "beyond reasonable doubt", an extremely high standard, which perhaps explains why there have been so few applications concerning people with mental disabilities. The "beyond reasonable doubt" standard has been criticised by the judiciary, one Strasbourg judge eloquently expressing his opinion that the standard of proof required by the Court in torture cases to be "legally untenable and, in practice, unachievable", going on to point out that the Strasbourg Court "is the only tribunal in Europe that requires proof "beyond reasonable doubt" in non-criminal matters"[116]

Although it may prove difficult for detainees to obtain evidence of ill-treatment by their warders, allegations of ill-treatment must as far as possible be supported by appropriate evidence. Gathering

---

[109] Dougoz v. Greece Application No. 40907/98, judgment 6 March 2001, paragraph 46

[110] Price v. the United Kingdom Application No. 33394/96, judgment 10 July 2001

[111] Price v. the United Kingdom *op cit*, paragraph 30

[112] Peers v. Greece, Application No. 28524/95, judgment 19 April 2001, reported at (2001) 33 EHRR 51

[113] See for example Dougoz v. Greece *op cit*

[114] Selmouni v. France Application No. 25803/94, judgment 28 July 1999, reported at (2000) 29 EHRR 403

[115] *ibid*

[116] Partly dissenting opinion of Judge Bonello in Veznedaroglu v. Turkey Application No. 32357/96, judgment 11 April 2000, paragraph O-I12

sufficient evidence may be difficult if the applicant is or has been detained in a psychiatric institution. The patient may not have access to the outside world, and may be too medicated to do anything about it. Judges are notoriously deferential to professionals and sometimes simply do not believe the testimony of someone with a psychiatric diagnosis. A commonly held prejudice is that people with a mental disability deserve different (lesser) standards than others: *situations which are unacceptable for me are acceptable for them*. There is no doubt that inhuman and degrading treatment exists in many institutions throughout Europe. Activists must be aware of real and practical difficulties of accessing justice, and may have to think about creating innovative strategies to both encourage litigation and to protect clients, a topic to which we will return.

Obligation to investigate allegations of Article 3 violations

In the landmark case of Assenov v Bulgaria,[117] the Court held that States are under an obligation to carry out an effective investigation where a person raises an arguable claim that s/he has been the victim of an Article 3 abuse by State agents. The investigation “should be capable of leading to the identification and punishment of those responsible … If this were not the case, the general legal prohibition of torture and inhuman and degrading treatment and punishment, despite its fundamental importance, would be ineffective in practice and it would be possible in some cases for agents of the State to abuse the rights of those within their control with virtual impunity.”[118] States are therefore mandated to establish workable complaints procedures in all institutions including hospitals, long-stay homes and children’s homes. Individuals can complain to Strasbourg alleging that there was no effective investigation of a credible claim of an Article 3 violation.

The right to respect for private and family life, home and correspondence

Article 8 of the Convention provides:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The Court has defined the concept of private life to include “a person’s physical and psychological integrity” [119] maintaining that “respect for private life must also comprise to a certain degree the right to establish and develop relationships with other human beings”.[120] The Court has recently spelled out that “mental health must also be regarded as a crucial part of private life associated with the aspect of moral integrity”.[121]

In the psychiatric setting, Article 8 will be engaged by such diverse issues as diverse as freedom of correspondence, right not to be in a crowded living space, access to non-pharmacological therapy, access to fresh air and exercise, privacy in washing and toileting; privacy of visits, confidentiality of medical records; right to sexuality, right to be free from unwanted sexual advances; freedom from surveillance of daily life and searches of living space and of person.

---

[117] Assenov v. Bulgaria, Application No. 24760/94, judgment 28 October 1998, reported at (1999) 28 EHRR 652

[118] paragraph 102

[119] Botta v. Italy Application No. 21439/93, judgment 24 February 1998, reported at (1998) 26 EHRR 241

[120] Niemietz v. Germany Application No. 13710/88, judgment 16 December 1992, reported at (1992) 16 EHRR 97 (paragraph 29)

[121] Bensaid v. the United Kingdom Application No. 44599/98, judgment 6 February 2001, reported at (2001) 33 EHRR 10

Any interference under Article 8 must be "in accordance with the law", a provision intended to prevent arbitrary actions by State authorities, and intended to give legal certainty so that individuals may regulate their conduct accordingly. Any interference with privacy must be justified by the government "in pursuit of a legitimate aim", in reference to one of the categories listed in Article 8(2). Once the government has claimed that the interference is justified by reference to one of these categories, the Court will examine whether the measure is necessary in a democratic society, which means that "there must be evidence of a pressing social need".[122] The Court interprets the social needs of a democratic society by recognising that the hallmarks of a democratic society are broadmindedness, tolerance and pluralism.

The Court will examine the proportionality of any measure taken: are the reasons which the State advances for justifying an interference relevant and sufficient? The Court will examine the nature and degree of the interference of the person's rights: the more interference with a person's rights, the more justification is required for any interference. The Court allows States some flexibility in deciding whether an interference is justified, but this "margin of appreciation" varies from case to case, depending on the nature of the activity, the need for (and reasons given) for restricting it.

There have been remarkably few applications – successful or otherwise – alleging violations of Article 8 within psychiatric settings. The reason for this is not that there are no Article 8 abuses, but is rather explained by the practical and financial difficulties faced by patients wanting to take their cases to lawyers, issues which will be discussed below.

Correspondence

In Herzgefalvy v. Austria the Court stated that "in the field of detention in psychiatric institutions [where] all persons concerned are frequently at the mercy of the medical authorities, [...] their correspondence is their only contact with the outside world."[123] Telephone or electronic communications fall within the scope of Article 8. Interception of any private communication is, on the face of it, a violation of rights protected by Article 8. Governments may argue that the interception of communication is necessary in a democratic society, and therefore justified under Article 8(2).

The right to correspondence does not merely mean a right to be free from interference/interception, but also a right to communicate. Therefore States must not restrict communication.[124] At the outset it is clear that patients who are receiving inpatient psychiatric care and treatment who are *not* detained under national legislaiton, are able to send and receive mail as they wish.

In a mental health institution there may be concern that mentally disabled patients could send letters containing threatening or disturbing content which might cause distress to the recipient or put that person in danger. In a situation where a person with mental disability has committed a crime and is assessed as being dangerous *and* there is sufficient evidence which merits the action, the State's concern to protect other individuals by censoring mail may be justified under Article 8(2).[125]

In cases concerning prisoners' rights, the Court has said that the State has a positive obligation to assist a prisoner in maintaining contact with his family. Therefore an absolute prohibition on communicating with the outside world will invariably be a violation of Article 8, especially because there can be no punitive aspect involved in mental health care.

---

[122] Dudgeon v. United Kingdom (1981) 4 EHRR 149 (paragraph 51)

[123] Herzegfalvy v. Austria *op cit*, paragraph 91

[124] See Golder v. United Kingdom (1975) 1 EHRR 524 and Campbell and Fell v. United Kingdom (1984) 7 EHRR 165

[125] See Silver and Others v. the United Kingdom Applications Application Nos. 5947/72 6205/73, 7052/75, 7061/75 7107/75, 7113/75, 7136/75, judgment 25 March 1983, reported at (1981) 3 EHRR 475 (Comm Dir) and (1984) 5 EHRR 347 (Court)

There can be very few grounds to withhold incoming mail from people who are detained in psychiatric institution. If a person is detained in a forensic (criminal) institution, patients should be allowed to receive mail unless it can be shown that it is in the interests of safety of the patient or for the protection of others to withold incoming mail.

The right to consult and correspond with a lawyer has a special status under European human rights law. The Court has said that "correspondence with lawyers ... concern matters of a private a confidential character. In principle, such letters are privileged under Article 8".[126] Legal correspondence is privileged irrespective of whether the content concerns actual or intended litigation. Likewise, any interference with correspondence to or from a court (including the European Court of Human Rights) may be a violation of Article 8. In the case of Campbell the Court permitted opening of legal correspondence in certain circumstances:

> … [P]rison authorities may open a letter from a lawyer to a prisoner when they have reasonable cause to believe that it contains an illicit enclosure which the normal means of detection have failed to disclose. The letter should, however, only be opened and should not be read. Suitable guarantees preventing the reading of the letter should be provided, e.g. opening the letter in the presence of the prisoner. The reading of a prisoner's mail to and from a lawyer, on the other hand, should only be permitted in exceptional circumstances when the authorities have reasonable cause to believe that the privilege is being abused in that the contents of the letter endanger prison security or the safety of others or are otherwise of a criminal nature. What may be regarded as "reasonable cause" will depend on all the circumstances but it presupposes the existence of facts or information which would satisfy an objective observer that the privileged channel of communication was being abused.[127]

Medical treatment

Involuntary medical treatment, an invasion of bodily integrity, engages Article 8. The issue of involuntary medication and their side effects is a major complaint by many users of psychiatric services. In a case decided the same year as Herczegfalvy v. Austria, the Strasbourg Court held that that medical treatment, even with unpleasant side-effects, is justified by the need to protect a person's health and preserve public order.[128] In the future the Court may be invited to take a different view if the applicant can provide evidence that there were less-intrusive options were available but not used.

Investigation after death

The first sentence of Article 2 of the Convention, which is relevant for our purposes, reads, "Everyone's life shall be protected by law". The rest of the Article concerns executions and the use of force. The right to life ranks as one of the most fundamental provisions in the Convention, from which no derogation is permitted.

The jurisprudence of the Strasbourg Court concerning the right to life has developed in the last ten years following a number of cases of lethal state action. Article 2 imposes a negative obligation on States not to kill people, and a positive obligation to protect lives. Case law has also developed a set of procedural obligations, whereby a State must set up a legal system which properly investigates deaths. It is clear now that all deaths must be investigated, not just those which result from lethal State

---

[126] Campbell v. United Kingdom Application No. 13590/88, judgment 25 March 1992, reported at (1992) EHRR 137

[127] at paragraph 48

[128] Grare v. France Application No. 18835/91, reported at (1992) 15 EHRR CD 100 (Admissibility decision of the former European Commission on Human Rights)

action.[129] Where a death occurs in custody the State is under an obligation to provide a satisfactory explanation of why the death occurred. If this proves impossible, or the answer unsatisfactory, the Court will find that the death occurred as a result of acts or omissions of the State and find a violation of Article 2.[130]

In medical settings in general, States are obliged to have a judicial system for the investigation into (alleged) medical accidents.[131] Further, there must be "an effective independent system for establishing the cause of death of an individual under the care and responsibility of health professionals and any liability on the part of the latter"[132]

Many people across Europe are dying because the State institutions in which they live do not provide adequate heating, food or basic medical treatment. Reports by the Council of Europe's monitoring body, the Committee for the Prevention of Torture, Inhuman or Degrading Treatment or Punishment (CPT) have revealed grossly elevated death rates. When the CPT visited Poiana Mare Psychiatric Hospital in Romania in 1995 they examined the record of deaths and found that 25 out of 61 deaths in an 8 month period were explicitly attributed to "severe protein and calorific malnutrition". The overall mortality rate was in excess of 20% per annum.[133] In a visit to the Terter Social Care Home in Bulgaria in 1999 the CPT noted an increase in deaths at the Home, running to an annual mortality rate of 33%. Causes of death included asphyxia and hypothermia.[134]

In 2002 Amnesty International reported on the Dragash Voyvoda home for adult men with mental disabilities in Bulgaria.[135] 22 men died in 2001 from a population of 140, and Amnesty International was "concerned that most of the deaths were cause by lack of adequate medical treatment", and that the causes of death in 19 out of 22 cases were severe pneumonia and malnutrition. The report further describes the institution as "appalling and inappropriate for accommodation for any human being, particularly for people with special needs. The very physical conditions were such that they undermined rather than improved a person's health".[136] There are other credible reports of recent and alarmingly high rates of mortality in countries within central and eastern Europe and the former Soviet Union.

What form of investigation is required under the Convention? At the outset the Strasbourg Court has indicated that it is incumbent on the State to act on their own motion once the matter has come to their attention. They cannot leave it to the initiative of the next of kin either to lodge a formal complaint or to take responsibility of the conduct of any investigative procedures."[137]

In a recent landmark case the Strasbourg Court set some extremely high standards for investigating deaths. In Edwards v. the United Kingdom[138] a prisoner had killed his cellmate (the applicants' son), and under English law an "inquiry after homicide" was established to investigate how the death occurred. The inquiry panel consisted of five professionals chaired by a senior barrister. The inquiry met on 56 days over a period of 10 months. It sat in private but heard around 150 witnesses and a considerable number of others submitted written evidence. The final report ran to some 388 pages, reached numerous findings of defects and made recommendations for future practice.

---

[129] Ergi v. Turkey, Application No. 23818/94, judgment 28 July 1998, reported at (2001) 32 EHRR 18

[130] Salman v. Turkey Application No. 21986/93, judgment 27 June 2000, reported at (2002) 34 EHRR 17

[131] Isiltan v. Turkey Application No. 20948/92, admissibility decision 22 May 1995,

[132] William and Anita Powell v. United Kingdom Application No. 45305/99, admissibility decision 4 May 2000

[133] CPT report on 1995 visit to Romania, published 19 February 1998, ref CPT/Inf (98) 5

[134] CPT report on 1997 visit to Bulgaria, published 28 January 2002, ref CPT/Inf (2002) 1

[135] This is the first Amnesty International report on human rights and mental disability. It signifies a major and welcome expansion of the organisation's mandate

[136] Amnesty International report: "Bulgaria: Residents of Dragash Voyvoda are dying as a result of gross neglect". AI index EUR 15/004/2002, 15 April 2002

[137] Ilhan v. Turkey Application No. 22277/93, judgment 27 June 2000, reported at (2002) 34 EHHR 36

[138] Paul and Audrey Edwards v. the United Kingdom, Application no. 46477/99, judgment 14 March 2002, reported at (2002) 35 EHRR 19, case comment at (2002) EHRLR, 1, 120-123

The applicants complained that, as relatives of the deceased, they were denied their procedural rights under Article 2. They complained that the inquiry sat in private and so they were excluded from hearing evidence apart from the three days when they themselves gave evidence. They were not represented by counsel, nor were they able to ask questions to witnesses. They also complained that the inquiry panel did not have the power to compel witnesses (in fact two prison officers refused to give oral testimony to the panel). The Strasbourg Court agreed with the family's complaints. The lack of power to compel witnesses detracted from the inquiry's capacity to establish the facts relevant to the death, and thereby to achieve one of the purposes required by Article 2. Further, the Court, noting the applicants' close and personal concern, criticised the inquiry for sitting in private, adding that the family "cannot be regarded as having been involved in the procedure to the extent necessary to safeguard their interests."[139]

The Strasbourg Court has breathed life into Article 2. After a death a State is now obliged to hold an investigation which is conducted by an independent body (a prosecutor's deliberating in private is not good enough), which is open, is prompt, has the power to compel witnesses to attend and give evidence, allows relevant parties to be represented and to ask questions and which is thorough and rigorous and capable of imputing responsibility for a death. The legal systems in many countries fall short of these stringent requirements.

Litigating for mental disability rights

Space has not allowed this paper to address some major issues which affect the lives of people with mental disabilities. One such system is guardianship, whereby a person's civil, political and social rights (e.g. to manage financial affairs, to decide on place of residence, to vote) are taken away by the State and are given to another person to control. There have been very few cases about guardianship, but undoubtedly more will come and the Court's jurisprudence especially - Articles 5, 6 and 8 - will develop.

Further, it is a mistake to view the Convention as a panacea of rights protection. There are some topics which the Convention cannot help directly: for example the "right" not to live in a large institution, coupled with the "right" to less-restrictive community-based multi-disciplinary psychiatric services. It seems that de-institutionalization is a political, economic and moral issue: it is not a Convention issue *in itself*, but litigation under the headings discussed in this paper may prompt governments to introduce community-based services. Other international instruments and recommendations exist which are more detailed than the Convention and the Court's case law. These instruments may assist in formulating arguments in favour of de-institutionalization.[140] Lawyers and human rights activists therefore need to see litigation as only one, albeit important, tool in their social reform toolkit.

There have been relatively few judgments from the European Court on Human Rights concerning mental disabilities, but important developments have been made. The Strasbourg Court can only decide cases which come before it; that is to say, there must be an applicant who is classified as a victim before the Court will hear the case: the Court does not allow general challenges to law or practice.[141] The paucity of litigation from people with mental disabilities at the Strasbourg Court should, perhaps, be unsurprising. Other reasons for the lack of litigation may include: low levels of knowledge about rights and remedies, little access to the outside world by people living in institutions,

---

[139] <u>Edwards v. the United Kingdom</u> *op cit*, paragraph 84

[140] Human rights activists may lobby using instruments such as the United Nations Principles for the Protection of Persons with Mental Illness (Adopted by General Assembly resolution 46/119 of 17 December 1991), Principle 3 of which states that, "Every person with a mental illness shall have the right to live and work, to the extent possible, in the community."

[141] See Article 34 of the Convention

distrust of the legal system, and lack of human rights knowledge and/or enthusiasm by lawyers. The gulf of mental disabilities cases reaching Strasbourg is evidence of the fundamental and systemic problem of access to justice by people with mental disabilities, coupled with stigmatisation at every level in society including within the health and justice systems.

If we are to make any serious attempt to eradicate human rights violations within the mental disability sector, a number of different people must use a number of different tools. Among these strategies are human rights monitoring and report writing, the use of existing regional and international human rights monitoring bodies, advocacy at the local and national parliamentary and international level, media campaigns, education of professionals, and - perhaps most importantly - empowerment of user and carer organisations and individual users and carers.

Strategic litigation

Alongside these methods litigation is key, as it remains one of the strongest ways of achieving systemic change. Apart from courtroom victory, litigation has the potential to raise the public awareness, and to empower an otherwise vulnerable and disadvantaged group. A success in the Strasbourg Court slowly forces a country not only to follow an order of the Court to pay damages, but also to legislate to change aspects of the law or practice which the European Court has held to violate the Convention. The Council of Ministers of the Council of Europe has the responsibility to monitor the execution of judgments: at this stage litigation becomes a political issue which makes compliance with the Court's decision all the more likely.

In order to achieve systemic change, it is suggested that litigators develop test case litigation – that is, finding the right client for a case which has the potential to change the law or how it is applied, in a way which will affect not only the client, but people in similar situations. When pursuing a test case strategy lawyers working in the field of strategic litigation must be patient (not an easy task for lawyers) and think creatively to overcome obstacles. Among these obstacles may be access to remote institutions which are many hours drive away from major cities. Once inside an institution it may be very difficult to find adequate time and private space to talk to as many people as possible to find someone who is willing to become a client. The whole process may be unfamiliar and awkward for lawyers who are used to clients seeking out the law firm for assistance. Furthermore, lawyers may not feel comfortable working with "those kind of people", a prejudice born from having had little previous contact with people with a mental disability. Mental disability law is usually paid very poorly (if at all):[142] many lawyers are turned off working in this field for financial reasons.

It takes time to build up trust, to communicate, to gain instructions from a person with possible severe mental disabilities, and to convince that person that pursuing a legal remedy will help that person and others. There are also safety issues for a potential client. The powerful director of an institution could 'persuade' the client to drop the case, by taking away privileges, increasing medication, or arranging a "psychiatric" interrogation. Lawyers have an ethical responsibility to think through these issues and to ensure that the safety of their clients becomes and remains the primary concern.

Mainstreaming mental disability rights

It is crucial that human rights are respected at the grassroots level of service delivery. Mental disability professionals such as psychiatrists and nurses should receive training in human rights and ethical standards, and be encouraged to think in Convention terms: "By not allowing this telephone call, am I invading Mrs Smith's privacy? If so, what am I trying to prevent, and is what I am doing proportionate

---

[142] For example, in Hungary, lawyers are paid 1,000 Hungarian Forints (approximately four euro) gross for the first hour spent in court (note that the same is paid even if the hearing lasts two minutes). Nothing is paid for meeting the client before a hearing, or preparing the case

to those aims...?" Similarly, it is hoped that groups of professionals will become partners in human rights, not defensive opponents, as seems to be the case with the unmodified electro-convulsive therapy issue in Bulgaria[143] and caged-beds in Hungary.[144] After all, respect for human rights often brings with it better funding for services – an issue on which all professionals can agree.

Whilst focussing on groups such as refugees, children, women and death penalty prisoners, mainstream international human rights non-governmental organisations, such as Amnesty International and Human Rights Watch have been slow to recognise mental disability as an area of concern worthy of their attention.[145] Alarmingly few national human rights NGOs are concerned with protecting the rights of people with mental disabilities.

As well as litigators and NGOs, governments have responsibilities to recognise that people with mental disabilities are (have always been) entitled to respect for their human rights. In a major report, the WHO recommends that "[m]ental health policy, programmes and legislation are necessary steps for significant and sustained action. These should be based on current knowledge and human rights considerations".[146] Governments must fund services adequately to meet basic human rights standards *as well as* establishing de-institutionalization programs and developing meaningful community-based services. Consumers, family members and the wider community "should be included in development and decision-making of policy, programmes and services".[147] Ministries must engage with reform experts and become reformers themselves. The alternative is a series of governmental defeats in Strasbourg which, of course, is time-consuming, costly and embarrassing.

Mainstreaming "mental disability rights" into our regular human rights agenda is a crucial step towards thinking seriously about protecting the rights of people with mental disabilities. Vulnerable individuals in our societies deserve more than to be marginalized by intergovernmental bodies, governments, human rights organisations, lawyers and mental disability professionals. This recognition is but the first stage towards ensuring that people with mental disabilities are afforded the rights guaranteed by the European Convention on Human Rights, and that we are all able to live our lives free from interference, abuse and neglect.

---

[143] At a public conference on human rights and psychiatry in Sofia in January 2002, leaders of the Bulgarian Psychiatric Association refused to condemn the use of ECT without anaesthesia or muscle relaxants

[144] Similarly, in Hungary, the Hungarian Psychiatric Collegium refused to recommend the banning of caged beds when consulted by the Hungarian Parliament for their professional opinion regarding acceptable restraint methods

[145] Amnesty International's press releases on psychiatric institutions in Bulgaria in 2002 signal the organisation's first

[146] World Health Organisation, *World Health Report 2001 Mental Health: New Understanding, New Hope* (Geneva, WHO, 2001), p.xii

[147] *ibid*

FIFTH SESSION

Implementation of access to the rights, responsibility, monitoring and lobbying : the role of governments, NGO and civil society

CINQUIÈME SESSION

Mise en application de l’accès aux droits, la responsabilité, le contrôle et le lobbying: le rôle des gouvernements, les ONG et la société civile

IMPLEMENTATION OF / ACCESS TO THE RIGHTS, RESPONSIBILITY, MONITORING AND LOBBYING: THE ROLE OF GOVERNMENTS, NGOs AND CIVIL SOCIETY

Athanassios CONSTANTOPOULOS
M.D., DPM, MRCPsych., Dip. Psychother.
National Mental Health Counterpart to WHO Europe
National Political Health Coordinator for SEE
Director, Mental Health Centre (Greece)

PREAMBLE

I would like first of all to make clear that I do not consider myself an expert on human rights, and whatever I have to contribute to the discussion comes from the point of view of a professional and an active citizen.

For the purposes of this presentation, I have assumed that mental health legislation for the protection of the rights of persons with mental disabilities is in place, and I will concentrate on how to implement it best, in the areas delineated by the title of this session. I would like, therefore, to make only two general points about legislation.

1. That it should be realistic and take seriously into account the available resources, as well as the possible barriers to implementation of policies and programmes. In other words, account should be taken of the context of each particular country. Should it not, then sooner or later, it will fall into disrepute and become obsolete, thus adding to the disappointment, frustration and disillusionment of all concerned, a point already made by Mrs Orsolya Székely in her speech, when she talked about country specific legislation.

2. That there is a current debate going on about the need for special mental health legislation which incorporates the protection of rights of persons with mental disabilities. One side argues that such special legislation is indispensable for the protection of rights of persons with mental disabilities, while the other side argues that special legislation is stigmatizing by itself, and that general legislation concerning health provision should provide equally for physical and mental health, and for the rights of the people concerned. I also feel that whatever the case may be, we should take serious notice of Lord Alderdice's comment that equating mental with physical health (in an effort to put the former on an equal footing with the latter) may be strategically attractive, but perhaps not wise. The solution (or reasonable compromise for the time being) lies again with an approach that takes account of the context of each particular country. For example, in a country like Sweden, such a special law is probably a retrograde step, while in a country of the former Soviet bloc, it may be a necessary and a progressive step towards safeguarding the human rights of mentally disabled persons.

OBSTACLES TO EFFECTIVE IMPLEMENTATION

There are various factors impeding the effective implementation of mental health legislation. Amongst them, the main ones are:

1. Insufficient resources
2. Lack of knowledge among professional groups and the general public
3. Resistance to certain legal provisions, or the absence of supplementary guidelines.

As for who plays the main role, and who carries the main responsibility for facing the obstacles mentioned above, I would say that for point 1, the main responsibility lies with the government, for point 2 with the government, the professional bodies and training institutions and users and family organizations and other NGOs, and for point 3, primarily with the government, but with the involvement of various NGOs.

MECHANISMS FACILITATING IMPLEMENTATION

There are certain mechanisms that facilitate the implementation of mental health legislation, such as:

1. Advocacy and dissemination of information on the rights of persons with mental disability
2. Training of health personnel and personnel of other sectors in issues relating to persons with mental disability, and
3. Setting up review mechanisms to monitor the implementation of legislation, by conducting regular inspections of mental health facilities and reviewing cases of involuntary treatment and admission.

As far as the facilitating mechanisms are concerned, for point 1, ideally the main role and responsibility should lie primarily with NGOs and secondarily with the government and the professionals. Point 2 should primarily be the domain of the professionals and the government, and finally, point 3 should be primarily the responsibility of the government, but in the closest possible coordination with the various NGOs and the professionals.

LOBBYING AND/OR AWARENESS RAISING

There is debate about who is primarily responsible for lobbying/awareness raising, and who should play the main role in this field. Rule 1 of the UN Standard Rules demands the state to take action to raise awareness in society about rights, needs, potential and contribution of persons with disabilities. There is no doubt about the good intentions of Rule 1 of the UN, and yet somehow it feels awkward that out of its 9 points or directives, in only 3 of them it calls for the participation of or consultation with users or their families. On the other hand, users and family organizations increasingly voice their objection to such an approach (a state-driven one), claiming that this should be their responsibility primarily, if not exclusively. At the same time dedicated professionals (who struggled for the reform of the Mental Health Services) have, for a long time, seen and experienced this field as one of their main responsibilities towards their patients, and part of their role as carers.

I must confess that my sympathy lies with the users and their families. Ideally, it should be their job. Taking eventually their fate in their own hands is the only sure way to autonomy and equality. As long as others are primarily responsible for them (be it the state or professionals), even if it is done with the best of intentions, it will always carry the seeds of a benevolent paternalistic approach, which implicitly, or even explicitly, fosters dependency, thus undermining the way to autonomy and equality.

At the same time, we ought to be realistic. Users and families can be the leaders in this field, only where strong movements and associations already exist. In countries where these movements and associations do not exist, or are at an early stage of development, it should be primarily the responsibility of the state and secondarily that of professionals to play this role, but with the emphasis being on providing the support required for the development and empowerment of the users and families organizations, so that they can assume their role in this field at the earliest possible time.

Taking into consideration that even in the best of cases, the user and family associations have still a long way to go towards development and empowerment, there is a strong need for cooperation between all three parties, if they are to achieve the maximum possible results at the earliest possible time.

MONITORING

Before I move now to monitoring, I would like to acknowledge my debt in what follows to ideas generated in the Seminar “Let the World Know”, organized by the office of the Special Rapporteur on Disability and held in Stockholm, November 2000.

Monitoring of the extent to which the existing human rights charters and legislation are observed, is necessary. A knowledge base would thereby be created, thus ensuring that proper and documented information becomes available, and therefore it becomes easier to win public support for the defense of rights, and makes it also harder for governments to claim that there is no abuse in their country, and finally it ensures that gross abuse is reported immediately to UN. In addition, such a knowledge base could be used for educational and training purposes.

There are five components to monitoring.

Monitoring individual cases, which, through making cases visible, aims to raise awareness, or even reveal cover-ups. Any organization, to run such a monitoring programme, requires a “human rights specialist”, who will be the point of first contact, and the only person who can identify the victim. Confidentiality is of the utmost importance to protect the victim from possible retribution, but protection for the human rights specialist, and for other staff involved may also be required. The specialist should investigate, record, verify and report on the case to his NGO at local or country level, with reports collected centrally by the UN or by an INGO, which in turn reports to the UN.

Monitoring legal cases, (court cases and administrative decisions related to disability and rights) which could lead to the creation of an international database, ideally also available on the internet. This service can most appropriately be the responsibility of the Ministry of Justice at country level, reporting centrally to the office of the UN High Commissioner for Human Rights. It goes without saying that at the same time, there should also be a monitoring body safeguarding from possible slip-ups or sins of omission etc, of the Ministry of Justice. Such a monitoring body would ideally consist of a comprehensive group of representatives from legal institutions, and organizations with a special interest in human rights and disability.

Monitoring of the media, to monitor infringements reported in the media, and infringements by the media. Infringements reported in the media may be done so in a respectful manner, or may, by their way of presentation (eg. sensationalism), in and of themselves constitute an infringement. This function could be the responsibility of NGOs at country level, reporting centrally, either directly, or through an INGO to a global database such as the “Disability Rights Media Watch”, proposed at the Seminar that I have already mentioned.

Monitoring legislation. Legislation may protect, or it may create inequality and exclusion, or it may be silent (or incomplete), and by omission, allow or lead to inequality and exclusion. This kind of monitoring can best be done by a variety of bodies such as university departments (including those based on distance learning), research or social policy organizations, and national and international NGOs in the field of disability.

Monitoring programmes, services and practices. This function could be carried out by a comprehensive multidimensional reporting system, which could have at its disposal appropriate instruments (eg reporting manual), and could focus on particular programmes, services and practices, and could document the way in which the combination of law, policy, practice and social attitudes can have a cumulative impact. Disability NGOs can prepare shadow reports to be sent in addition to government reports for UN, and these could include intended and unintended infringements. To expedite the process, this could be done by NGOs in consultative status with the Economic and Social Council (ECOSOC) as they have direct access to UN organs and bodies.

The above five components have in common a structure, and a central collection point for information that is accessible, and therefore encourages reporting and follow-up action. Ideally, all five of them should be highly interactive in order to achieve maximum results.

CIVIL SOCIETY

I left the role of civil society for the end, as it is the most important, and at the same time, the most difficult to tackle. Up to now, I have focused more on changing or preventing discrimination, which primarily involves a legal agenda. In this part, I will turn to changing the stigma attached to mental disability, which mainly involves education to change beliefs and attitudes. Changing the mentality of the people is the most difficult task, whatever change we seek to bring about. In our case, it is even more difficult, because, through the ages, mentally disabled people have been the objects of outright persecution, scapegoating and discrimination, revealing society's fear, intolerance and reaction to the "different" or the "deviant", and at a deeper level, the fear in most, if not all of its members, of the two most dreaded conditions – death and madness. It goes, therefore, without saying, that in order to change this situation, we need the maximum possible cooperation between all parties involved, be it user, family, NGO, professional or government official.
But we need much more than this!

If we are to tackle issues of human rights, what we need primarily is a Citizen's Society. In ancient Greece, the term "idiotis" (in which the word *idiot* has its roots) meant the person who did not care about public issues and the affairs of the society in which he lived, pursuing only his self-interests – in other words, "minding his own business". The same connotations are attached to the Latin word "privare", and the nouns deriving from it "private" and "privacy" (ironically, most revered words in today's society). The opposite of the Greek "idiotis" is the word "politis", its exact translation being *citizen*. A person who actively participates in the life of the "polis" (*city*), fully aware that what goes on in the society in which he lives has, sooner or later, direct repercussions on his life.

So what we need is to strive for the transformation of our society to a Citizen's Society. Only through such a transformation can we really hope to tackle issues concerning human rights successfully. A transformation of this kind would also lead to reinstatement of trust as the basis of public relationships, reverse the current trend of human rights law and democratic accountability being used as a substitute for the lack of trust, a danger already stated by Lord Alderdice in his speech, and restore human rights to its proper position.

Therefore, the responsibility lies with every single one of us. Not as user, family member, professional or politician, but as an active citizen. A role and a task even more difficult in this age of globalization, and yet perhaps easier, should we decide to concentrate on and utilize its positive aspects, and not those most currently revered – such as competition, "success" and profit.

Should we accept such premises, then to my mind, our primary strategic targets for such a societal transformation should be our children and our grandchildren. We should make every effort to encourage them to become active citizens, and teach them, most importantly by our own example, from the earliest possible age, of the values of pluralism, respect for difference, and interest and compassion for their fellow human beings.

Allow me to illustrate this last point by showing you a picture which came to my attention only a couple of days ago. It was drawn by an 11-year-old girl. She is the granddaughter of Mrs. Begoňe Ariňo, EUFAMI President, and she demonstrates in the most effective way the results of such an upbringing. I would only like to add that the figures of the neighbours, on the left side of the picture, waving in a friendly manner to the man, represent the end results of the efforts Mrs. Ariňo has made with her neighbours, to accept her son, efforts which she spoke about in a previous session.

Yesterday, Professor Lars Jacobsson insistently put to us the question “What does it mean to respect a psychotic person?” A Zen master could have answered this question by “it means to respect a psychotic person”, but I feel that the drawing of this 11 year old girl answers the question much more clearly, and points directly to the path that we should follow, if our aspirations about the rights of mentally disabled people were to become a reality.

*By kind permission of Mrs. Begoňe Ariňo, EUFAMI President (see below for English text)


I AM NOT MAD
I think someone is following me
I want to be alone
I hear voices
Don't make fun of me
They are laughing at me
A PERSON WITH A MENTAL ILNESS IS A NORMAL PERSON
Annica López
11 years old

BACKGROUND DOCUMENTS

Universal Declaration of Human Rights, G.A. res. 217A (III), U.N. Doc A/810 at 71, 10/12/1948

Convention for the Protection of Human Rights and Fundamental Freedoms, Rome, 04/11/1950

Standard Rules on the Equalization of Opportunities for Persons with Disabilities, UN A/RES/48/96, 20/12/1993

European Social Charter (revised), Strasbourg, 03/05/1996

“Let the World Know”, Report of a Seminar on Human Rights and Disability, Stockholm, 05-09/11/2000

CLOSING SESSION

SESSION DE CLOTURE

Closing speech by / Discours de clôture par :

Alexandre JOLLIEN,
Philosopher / Philosophe (Switzerland/Suisse)

J'ai à cœur de remercier le commissaire pour l'insigne honneur qu'il me témoigne en me laissant conclure ce séminaire. J'ai particulièrement apprécié sa réflexion et constate que, seul, le commissaire a parlé d'intégration. Pourtant l'intégration devrait être au centre de la promotion des droits de l'homme des personnes handicapées mentales ou psychiques.

M'adresser à une assemblée de psychiatres et de spécialistes ne va pas sans craintes et tremblements. Au moment de parler, je ne peux oublier que les psychiatres qui m'ont suivi m'ont doté, pour les besoins de leur diagnostic, d'un Q.I. inférieur à la norme, ces spécialistes ne m'ont certes pas donné accès à la parole. D'ailleurs qui peut se targuer d'être spécialiste quand il s'approche d'un homme ? Le Commissaire en donnant la parole à un marginal inaugure un dialogue trop fréquemment interdit. Les marginalités, en effet, trop souvent réduites au silence ont le droit de participer à la promotion de leurs droits.

En parcourant la Charte européenne des personnes autismes me viennent quelques idées que je vous soumets en toute simplicité :

La Charte parle du droit à un diagnostic. J'ajouterai droit à un diagnostic revisité. Se peut-il qu'un diagnostic trop prompt induise un handicap ? Trop souvent une pathologie, un terme, une appellation suivent un patient tout au long de leur vie et déterminent son avenir. Le praticien ne voit alors que la pathologie et oublie que derrière l'étiquette, que derrière le diagnostic se cache une personne toujours plus dense que ce que l'on en perçoit. Je ne critique pas la notion de diagnostic mais j'insiste sur sa valeur heuristique. Le diagnostic est là pour déployer les ressources les plus adaptées aux difficultés rencontrées par le patient. Le praticien doit le réajuster pour qu'il soit plus fidèle au patient.

Le droit à la non-réduction doit aussi guider la pratique du médecin. Trop souvent le patient devient un client, le porteur d'une pathologie. Un danger apparaît dès lors : oublier que derrière le porteur de la pathologie se dresse toujours un être humain, digne de respect, bénéficiaire des droits de l'homme et sujet de devoirs. Le psychiatre qui, ce matin, nous a donné un cours de littérature ne doit pas oublier que Lord Byron n'est pas qu'un anorexique, que Proust ne se réduit pas à une dépression. Au même titre, le malade n'est pas qu'un malade.

Le droit à la décision. Nombre de professionnels ont pour fâcheuse habitude de parler « sur » les personnes handicapées mentales. L'entomologiste qui parle sur le scarabée ou la mouche doit incarner le danger qui guette le professionnel. Le principal concerné, le patient, est-il véritablement au centre de la décision ? On rétorquera que les patients n'ont souvent pas accès à la parole, qu'ils ne bénéficient pas des outils verbaux nécessaires. Pour avoir vécu aux côtés de tels individus, je ne puis me contenter de semblable contre argument. Le talent du professionnel ne consiste-t-il pas précisément à dévoiler les intérêts de chacun ? Prêter l'oreille à des signes, à un détail, à un message sans cesse menacé, voilà l'exigence devant laquelle se trouve le professionnel.

Droit à la culture. Récemment, j'ai rencontré des personnes trisomiques vivant dans une institution. Ces derniers m'ont surpris par leurs connaissances. L'éducateur posait une question sur la date de naissance de Courbet. Et les personnes handicapées mentales rivalisaient pour donner la réponse exacte. Ils m'ont appris quelque chose. Ils m'ont apporté une connaissance. La culture peut être un important instrument d'intégration. Sur le handicap objectif, médical peut se greffer un handicap social, un manque de repères qui isole encore davantage le malade et induit des comportements inadaptés.

Droit à une institution ouverte. Dr Athanassios Constantopoulos a rappelé l'étymologie de *idiotis* à savoir celui qui ne se préoccupe pas des affaires sociales. J'aimerais à mon tour convier un autre grec. Aristote faisait de l'homme un animal politique. *O anthropos zoon politikon*. L'homme se constitue grâce à l'autre. Il naît de et dans la relation aux autres. Ainsi l'individu qui vit à perpétuité dans une institution ne se ferme-t-il pas à cette richesse qui grandit l'être humain ? Dans la même perspective, mon expérience de 17 ans d'institution m'a appris combien est grand le rôle de l'affection. La vie d'une personne handicapée est un combat permanent. Ce combat nécessite beaucoup de motivation laquelle se nourrit avant tout d'affectivité. Or placer un être humain au milieu de techniciens qui affichent une distance thérapeutique sans nuances, a priori, et intransigeante, procède selon moi d'une forme de maltraitance. Il n'est que d'interroger des pensionnaires pour s'en convaincre.

Droit à la transparence. Les institutions risquent de devenir des zones de non-droit ou plutôt de non-contrôle. Car la transparence rencontre maints obstacles. Un éducateur qui s'occupe de personnes handicapées mentales profondes me disait ne pas savoir la limite exacte entre la prise en charge thérapeutique et l'abus de pouvoir. En effet comme le séminaire l'a révélé, l'abus sur des personnes aussi vulnérables que les malades psychiatriques ou handicapés mentaux est un danger qui doit être à tout prix éliminé par plus de transparence, davantage de remises en question et de contrôle.

Droit à une bonne image. Le séminaire conjugue, avec sagacité, la protection et la promotion des droits de l'homme des personnes psychiatriquement ou mentalement atteintes. Nous avons beaucoup parlé des luttes anti-stigmatisation. Intégrer les personnes concernées dans cette noble entreprise, leur donner la parole, et une fois de plus je ne nie pas la difficulté de la tâche, me semble primordial. Je conclurai en soulignant qu'il faut avant tout rassembler les diverses minorités. Il suffit de fréquenter les milieux marginaux, et notamment la prison, pour constater que nous sommes tous égaux devant la différence. Et voilà une des grandeurs des droits de l'homme. Les droits de l'homme s'adressent à ceux que Jean-Claude Guillebaud appelle *le principe d'humanité* qui habite chacun d'entre nous, le handicapé physique, le handicapé mental, le criminel, le malade dans le coma. Tous les marginaux sont unis dans le même combat. Les mêmes préjugés pèsent sur eux. Promouvoir les droits des marginaux n'est pas un rôle annexe des droits de l'homme mais au contraire reflète sa vocation première. Avec les marginalités, il s'agit de promouvoir l'humanité de chaque homme.

L'enjeu est social mais l'entité sociale me paraît trop vague, trop floue, trop éloignée de la vie pour avoir un réel impact. Je crois davantage aux individus, à leur impact et en ce sens, le séminaire commence demain grâce aux fruits que nos discussions généreront dans la pratique, grâce au travail de chacun.

APPENDICES / ANNEXES

APPENDIX A

CONCLUSIONS OF THE SEMINAR

The Commissioner for Human Rights has, in the course of his official visits to member States of the Council of Europe, frequently had occasion to examine and express his concern over the respect for the human rights of persons with mental disabilities.

Convinced of the significant improvements that could be made throughout Europe and of the need to highlight, in the European Year of People with Disabilities, the particular, and frequently neglected, situation of persons with mental disabilities, the Commissioner invited legal and psychiatric experts, government officials, NGOs, family and user association representatives to examine these issues in greater detail in Copenhagen, at the seat of the World Health Organization Regional Office for Europe from 5 to 7 February 2003.

The Commissioner would like to express his gratitude to all the participants and, especially, to the World Health Organization for its cooperation in the organisation of this seminar and its ongoing contribution to the mainstreaming of the human rights situation of persons with mental disabilities.

On the basis of the discussions, the Commissioner presents the following conclusions.

1. The entitlement to the enjoyment of human rights admits no hierarchy of holders. Persons with disabilities, whether physical or mental, enjoy, in virtue of the respect due to their human dignity and integrity, the same human rights, in equal measure, as all other persons.

2. At the same time, the place and treatment of persons with mental disabilities in our society continues to be undermined by ignorance, prejudice and stigma. Discrimination and the exploitation of vulnerability remain widespread. The dehumanisation of persons with mental disabilities and the subsequent loss of their status as subjects of human rights are to be countered at every turn and with all available means. The World Health Organization estimates that 1 in 4 persons will, at some stage in their lives, experience mental health problems, some of whom will go on to experience sever and enduring mental disabilities. The protection of the human rights of such a marginalized group is, therefore, by no means, a marginal concern.

3. Whilst the fundamental task in this area must remain the implementation of existing norms and best practices, the elaboration of more detailed instruments, such as a United Nations Convention on the Rights of the Disabled, and the ratification of existing ones, in particular Article 15 of the revised European Social Charter of the Council of Europe, is to be welcomed and encouraged.

4. Legislative and practical initiatives impacting on the rights of persons with mental disabilities ought to include the broadest possible consultation with all the actors concerned, including members of the legal and medical profession, families and, most importantly, the community of mentally disabled persons directly concerned.

5. Every effort should be made to secure the provision of psychiatric care on basis of the informed consent of the individual concerned. The Commissioner recognises, however, that the involuntary placement or treatment of persons with mental disabilities may prove necessary in exceptional circumstances.

6. The jurisprudence of the European Court of Human Rights, the Substantive Guidelines of the Committee for the Prevention of Torture (CPT) and the 1991 UN Principles for the protection of persons with mental illness and the improvement of mental health provide clear instructions and minimum procedural guarantees to be respected in such circumstances. It is important to recognise that the compulsory placement and treatment of an individual are two separate questions requiring separate decisions. The existence of a mental disorder necessitating placement or treatment must be certified by an objective medical authority and it must be possible for the individual concerned to challenge the lawfulness of decisions authorising placement and/or treatment before an independent judicial or other appropriate review body. The regular review by an independent authority of the continued need for placement or treatment is an essential guarantee, which must be provided.

7. Persons with mental disabilities are particularly vulnerable to abuse, both within the community and in institutions. The living conditions and treatment of patients in mental institutions are frequently far from satisfactory. Dilapidated material surroundings, remote locations, inadequate care and poorly trained staff often give rise to serious violations of fundamental rights. An improvement in the living conditions and quality of care in institutions could frequently be provided with minimal additional expenditure. It is a question of political will. It is to be recalled that the respect for the right to health requires the investment, within the limits of the national budget, of the necessary means.

8. The development of effective support and community care services is to be encouraged as a preferable alternative to unnecessary prolonged institutionalisation. It is important that the services offered to persons with mental disabilities, whether in institutions or in the community, reflect the broad range of their needs. Assistance regarding the enjoyment of other fundamental rights, such as access to education, employment and certain civil and political rights encouraging greater social participation, ought to be furthered through the provision of multi-disciplinary support. Special attention must be paid to the provision of physical health care to all persons with mental disabilities, whether in institutions or in the community, who may not be in a position to insist themselves on the enjoyment of this right.

9. The access to justice of persons with mental disabilities remains a central concern, particularly, but not exclusively, for those residing in large, remote and impersonal psychiatric institutions. The knowledge of the rights of residents is frequently poor, both on the part of the residents themselves and those responsible for their care. Information on the rights of residents ought, therefore, to be broadly disseminated and

constantly available within institutions. Difficulties frequently arise in respect of patient contacts with the outside world – respect for the right to privacy is essential to securing access to telephones and correspondence. Greater efforts are required to ensure the access of persons with mental disability to appropriate legal aid.

10. In addition to effective internal complaint procedures, the frequent visiting of psychiatric institutions by independent inspection mechanisms greatly reduces the potential for human rights abuses. The access to such institutions by appropriate NGOs, user and advocacy groups is also to be encouraged. Persons with mental disabilities residing in the community cannot be excluded from monitoring procedures. It is particularly important, in this context that the confidentiality of information disclosing abuses is respected and that whistle-blowers are protected.

11. Legislation and practises in several countries relating to the judicial finding of incapacity and the placement under guardianship give rise to concern. The transfer of civil, political and welfare rights with inadequate or only formal judicial control obviously opens up the possibility of abuse by unscrupulous family members, “professional guardians” and directors of institutions. The implementation of Recommendation No. R(99)4 of the Committee of Ministers of the Council of Europe on Principles concerning the legal protection of incapable adults would greatly reduce such abuses, whilst enabling people to act appropriately on behalf of others in need of assistance.

12. Indeed, the implementation of these and other norms must remain the priority. National and international human rights protection mechanisms all have a role to play here. At the national level Ombudsmen, Human Rights Institutions and Discrimination and Disability Commissions can all make positive contributions with the necessary support and involvement. At the international level human rights monitoring mechanisms such as those provided for by the UN treaty monitoring bodies and the Revised European Social Charter are to be supported. Greater civil society involvement in these mechanisms, through the submission of shadow reports or the use of the Social Charter’s collective complaints procedure, is to be encouraged.

13. Significant advances will not be made, however, without the necessary political will and commitment of legislators to realistic policies. The constructive involvement of all actors, including persons with mental disabilities themselves, their families, politicians, the legal and medical professions and NGOs is vital. These actors are partners, not antagonists, and they all have a contribution to make.

14. What is ultimately required, though, is a shift in the attitude of society at large. A shift from exclusion to inclusion, from marginalisation to integration. A shift which must pass through the recognition of the special needs of person with mental disabilities and the positive contribution they can make to society. Broad social awareness and education must, therefore, be continually and actively promoted. Thereafter, it is the responsibility of each individual member of society to acknowledge, accommodate and respect the difference and dignity of all persons with mental disabilities.

ANNEXE A

CONCLUSIONS DU SEMINAIRE

Dans le cadre de ses visites officielles aux Etats membres du Conseil de l'Europe, le Commissaire aux Droits de l'Homme a eu souvent l'occasion d'examiner la manière dont sont respectés les droits des personnes handicapées mentales et d'exprimer ses préoccupations dans ce domaine.

Convaincu des améliorations importantes qui seraient possibles dans toute l'Europe et de la nécessité de souligner, en cette Année européenne des personnes handicapées, la situation spécifique et souvent négligée des personnes handicapées mentales, le Commissaire a invité des experts juridiques et psychiatriques, des représentants des gouvernements, des ONG, des représentants des familles et des associations d'usagers à examiner ces questions de manière approfondie à Copenhague au siège du Bureau régional de l'OMS pour l'Europe, du 5 au 7 février 2003.

Le Commissaire souhaite remercier tous les participants, et surtout l'Organisation Mondiale de la Santé pour sa coopération dans l'organisation de ce séminaire et pour sa contribution permanente à la promotion et à la défense des droits des personnes handicapées mentales.

Sur la base de ces discussions, le Commissaire présente les conclusions suivantes :

1. En ce qui concerne les droits de l'homme, il n'y a pas de hiérarchie entre les personnes. Les personnes handicapées, qu'elles souffrent de handicaps physiques ou mentaux, jouissent, en vertu du respect dû à la dignité et à l'intégrité humaine, des mêmes droits que tous les autres individus, et ce dans une égale mesure.

2. Pourtant, la place et le traitement des personnes handicapées mentales dans notre société sont encore marqués par l'ignorance, les préjugés et la stigmatisation. Elles souffrent fréquemment de discrimination et certains exploitent leur vulnérabilité. Il faut s'opposer à tout moment et avec tous les moyens possibles à la déshumanisation des personnes souffrant de handicaps mentaux et à la perte de leur qualité de sujets des droits de l'homme. L'Organisation Mondiale de la Santé estime que 2,5 % des personnes connaîtront à un moment de leur vie des problèmes de santé mentale, parmi lesquelles certaines souffriront de handicaps mentaux graves et durables. La protection des droits d'un groupe aussi marginalisé ne constitue donc absolument pas une préoccupation futile.

3. Alors que la tâche essentielle dans ce domaine doit rester la mise en œuvre des normes et des meilleures pratiques en vigueur, il faut saluer et encourager l'élaboration d'instruments plus détaillés, comme le projet de Convention des Nations Unies sur les droits internationaux des personnes handicapées, ainsi que la ratification des instruments existants, notamment l'article 15 de la Charte sociale européenne révisée du Conseil de l'Europe.

4. Les initiatives législatives et pratiques ayant des incidences sur les droits des personnes handicapées mentales doivent s'appuyer sur la plus vaste concertation possible de tous les acteurs concernés, y compris les membres des professions juridiques et médicales, des familles et, ce qui est plus important, de la communauté des personnes handicapées mentales directement concernées.

5. Tout doit être fait pour assurer la fourniture de soins psychiatriques sur la base du consentement éclairé de la personne concernée. Le Commissaire reconnaît cependant qu'il peut s'avérer nécessaire, dans des circonstances exceptionnelles, de placer ou de traiter des personnes handicapées mentales sans l'accord de ces personnes.

6. La jurisprudence de la Cour européenne des Droits de l'Homme, les normes du Comité européen pour la prévention de la torture (CPT) et les principes des Nations Unies de 1991 pour la protection des personnes atteintes de maladie mentale et l'amélioration des soins de santé mentale fournissent des instructions claires et des garanties minimales concernant les procédures à respecter dans ces circonstances. Il importe de reconnaître que le placement et le traitement obligatoires d'une personne sont deux questions distinctes nécessitant des décisions distinctes. L'existence d'un trouble mental requérant un placement ou un traitement doit être certifiée par une autorité médicale objective et l'individu concerné doit pouvoir contester la légalité des décisions autorisant le placement et/ou le traitement devant un organe judiciaire indépendant ou autre organe de révision appropriée. La révision régulière par une autorité indépendante de la nécessité de continuer le placement ou le traitement constitue une garantie essentielle à respecter.

7. Les personnes handicapées mentales sont particulièrement vulnérables aux abus, tant au sein de la collectivité que dans les institutions. Les conditions de vie et le traitement des malades dans des établissements psychiatriques sont fréquemment très inadéquats. Des installations vétustes, des lieux isolés, l'insuffisance des soins et un personnel peu formé sont souvent à l'origine de graves violations des droits fondamentaux. Dans de nombreux cas, un minimum de dépenses supplémentaires permettrait d'améliorer les conditions de vie et la qualité des soins dans les institutions. C'est une question de volonté politique. Il faut rappeler que le respect au droit à la santé exige d'investir les moyens nécessaires dans les limites du budget national.

8. Il faut préférer le développement de services efficaces de soutien et de soins communautaires à d'inutiles longs séjours en institution. Il est important que les services offerts aux personnes handicapées mentales, qu'elles vivent en institution ou dans la collectivité, reflètent la diversité de leurs besoins. Une aide concernant la jouissance d'autres droits fondamentaux, comme l'accès à l'éducation, à l'emploi et certains droits civils et politiques encourageant une plus grande participation à la vie sociale, devrait être fournie par l'intermédiaire d'un soutien multidisciplinaire. Il faut apporter une attention spéciale à la fourniture de soins de santé à toutes les personnes handicapées mentales, qu'elles vivent en institution ou dans la collectivité, car elles ne sont pas toujours en mesure de faire valoir elles-mêmes ce droit.

9. L'accès à la justice des personnes handicapées mentales demeure très préoccupante, notamment, mais pas seulement, pour celles qui résident dans de grands établissements psychiatriques isolés et impersonnels. Les droits des résidents sont souvent mal connus, tant par les résidents eux-mêmes que par ceux responsables de leur prise en charge. Par conséquent, l'information concernant les droits des résidents doit être largement diffusée et disponible en permanence au sein de ces établissements. Des difficultés se posent souvent concernant les contacts des malades avec le monde extérieur – le respect au droit à la vie privée est essentiel pour garantir l'accès à des téléphones et à la correspondance. Il faut redoubler d'efforts pour assurer l'accès des personnes handicapées mentales à une aide judiciaire appropriée.

10. Outre des procédures de réclamation internes efficaces, la visite fréquente des établissements psychiatriques par des mécanismes d'inspection indépendants limiterait beaucoup les risques de violation des droits de l'homme. Il faut aussi encourager l'accès à ces institutions par des ONG, et par des groupes d'usagers et de défense appropriés. Les personnes handicapées mentales résidant dans la communauté ne peuvent être exclues des procédures de contrôle. Il est particulièrement important dans ce contexte de respecter la confidentialité des informations révélant des violations et de protéger ceux qui dénoncent les abus.

11. Dans plusieurs pays la législation et les pratiques concernant les décisions judiciaires en matière d'incapacité légale et le placement sous tutelle sont préoccupantes. Le transfert des droits civils, politiques et sociaux avec un contrôle judiciaire insuffisant ou purement formel ouvre évidemment la porte à des abus de la part de membres des familles, de tuteurs professionnels et de directeurs d'établissement dénués de scrupules. La mise en œuvre de la Recommandation (99) 4 du Comité des Ministres du Conseil de l'Europe sur les principes concernant la protection juridique des majeurs incapables permettrait de réduire considérablement le nombre de ces abus tout en permettant à des personnes d'agir de manière appropriée pour le compte d'autres ayant besoin de leur aide.

12. En fait, la mise en œuvre de ces normes et d'autres doit demeurer prioritaire. Les mécanismes nationaux et internationaux de protection de droits de l'homme ont tous un rôle à jouer à cet égard. A l'échelon national, les médiateurs, les institutions des droits de l'homme et les commissions de lutte contre la discrimination à l'encontre des personnes handicapées peuvent tous contribuer efficacement en apportant leurs nécessaires soutien et participation. Au niveau international, il convient de soutenir les mécanismes de contrôle des droits de l'homme tels que ceux fournis par les organes contrôlant la mise en œuvre des conventions des Nations Unies et la Charte sociale européenne révisée. Il faut encourager une plus grande implication de la société civile dans ces mécanismes, avec la présentation de rapports par des ONG («shadow reports») ou l'utilisation de la procédure de réclamations collectives de la Charte sociale.

13. Cependant, il n'y aura pas de progrès significatifs sans la volonté politique et l'engagement nécessaires des législateurs en faveur de politiques réalistes. Il faut absolument impliquer de manière constructive tous les acteurs, y compris les

personnes handicapées mentales elles-mêmes, leurs familles, les responsables politiques, les professions juridiques et médicales et les ONG. Tous ces acteurs ne sont pas antagonistes mais partenaires et ont tous une contribution à apporter.

14. Ce qu'il faut, en fin de compte, c'est un changement d'attitude de la société tout entière. Passer de l'exclusion à l'inclusion, de la marginalisation à l'intégration. Ce changement doit passer par la reconnaissance des besoins spécifiques des personnes handicapées mentales et de la contribution qu'elles peuvent apporter à la société. Par conséquent, il faut promouvoir en permanence des actions de sensibilisation et d'éducation de la population. Chacun est appelé à reconnaître, accepter et respecter la différence et la dignité de toutes les personnes handicapées mentales.

APPENDIX B

Programme

Wednesday, 5 February

15h00: Opening ceremony

Speakers:

Mr Alvaro Gil-Robles, Commissioner for Human Right of the Council of Europe
Mr Lars Loekke Rasmussen, Danish Minister for the Interior and Health,
Special guest *Mr. Paulo Coehlo*, author
Dr Andres Lehtmets, first Vice-President of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)
Dr Marc Danzon, Regional Director of WHO Regional Office for Europe

Thursday, 6 February

9h - 9h45
SESSION 1: **Mental Health and Human Rights**

Speakers:
Prof Stephen Marks, Director of François-Xavier Bagnoud Center, Harvard School of Public Health, USA; and
Lord Alderdice, Speaker of the Northern Ireland Assembly
Intervener:
Mr John Henderson, Mental Health Europe

This session will give a general introduction to the relation between mental health and human rights and to mental health as an aspect of the human right to health. The definition of health contained in the preamble to the Constitution of WHO conceptualises health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Mental disabilities is a general term and includes many kinds of situations, but difficulty in adapting to moral, social, political and other values, in itself, should not be considered a mental disability. To balance between different rights such as the right to health and treatment and the right to freedom and integrity can often be difficult.

10h15 – 12h15
SESSION 2: **Restrictions on liberty: procedures and criteria for involuntary and non-voluntary placement and treatment**

Speaker:
Ms Orsolya Szekely, lawyer, European Court of Human Rights
Intervener:
Prof Lars Jacobsson, Department of Psychiatry, Umeå University, Sweden

Many persons, including minors, affected by mental disabilities are subject to involuntary and non-voluntary placement and / or treatment. This is an attaint to the physical freedom of the person. The laws and rules regarding the criteria and procedures of involuntary and non-voluntary placement and / or treatment and its review and termination should ensure that the human rights of the person concerned are respected particularly in relation to the ECHR, the Convention on Bioethics and the norms of the CPT. The White Paper also points to important questions to discuss. The situation of vulnerable groups such as children and the elderly should be given special attention.

13h30 – 16h30
SESSION 3: **Integrity and dignity**

Speaker:
Prof. Hilary Brown, Canterbury Christ Church University, UK
Intervener:
Mr Karl Bach Jensen, World Network of Users and Survivors of Psychiatry

Once the person with mental disabilities is placed and / or treated involuntary, the person often finds himself/herself in risk-situations where his/her rights are threatened. Consent to treatment and placement, guardianship, respect for one's privacy, ill treatment, general life conditions etc are issues that need to be addressed. In many countries there still exist large residential institutions for persons with mental disabilities where the conditions are under all critique. The situation of vulnerable groups such as children and the elderly should be given special attention. The White Paper and the remarks made by the CPT in part III of its 8th general report point out important issues.

Friday, 7 February

9h – 12h
SESSION 4: **Equality, non-discrimination and social justice: employment, education, health care, social security**

Speaker:
Mr Lars Lööw, Disability Ombudsman, Sweden
Intervener:
Prof Arthur Crisp, Director of Changing Minds Campaign, Royal College of Psychiatrists, UK

Equal status, inclusion and full citizenship and the right to choose should be promoted and implemented. To be able to participate fully in society, the access to education, social security, health care and employment are some of the areas of everyday life, which need attention. The need to make reasonable accommodation for persons affected by mental disabilities should be stressed. The right to equal access to rights should not be rigid so as to focus too much on the equal treatment but rather focus on the outcome of an action or omission to act. Instead of demanding that those with a disability adapt to their situation and the environment around them, it is only fair to demand of the surrounding environment to make provisions for facilitating the access to public and private life in order to perceive persons with mental disabilities not as problems but as a persons having rights and being assets to societal tolerance, pluralism, development and enriching the society. Art 15 of the revised Social Charter and the UN Standard Rules are of specific relevance. Women, children, persons belonging to a national / ethnical minority and the elderly who are affected by a mental disabilities are particularly vulnerable. These persons belong to groups that are often subject to discrimination and/or difficulties to protect their rights irrelevant of their mental disabilities and so there can be a double discrimination. Special attention should be paid to them.

13h30 – 15h
SESSION 5: **Implementation of / access to the rights, responsibility, monitoring and lobbying: the role of governments, NGOs and civil society**

Speaker:
Dr Athanassios Constantopoulos, Mental Health Centre, Greece
Intervener:
Mr Klaus Lachwitz, Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e. V., Germany

The ratification of relevant international instruments should be encouraged, in a European context especially the revised Social Charter (art 15). However, no laws, rules or policies are of any use if they are not properly implemented. The international conventional duty is on the state. In order to supervise and promote the effectiveness of the rights of persons with mental disabilities it might be considered to have specific organs or bodies within the state but also an open-minded dialogue and cooperation with civil society, in particular users groups, NGOs and with the professionals concerned. Persons affected by mental disabilities are often subject to discriminatory practices and attitudes in all sets of life. This is often due to a lack of awareness among professionals and the general public on what mental disabilities are; prejudices as well as structural and legal discrimination. Rule 1 of the UN Standard Rules demand the state to take action to raise awareness in society about the rights, needs, potential and contribution of persons with disabilities. There should be cooperation between government and NGOs on this issue.

15.30-17.00
SESSION 6: **Conclusions**
Mr Alvaro Gil-Robles, Commissioner for Human Rights of the Council of Europe

Closing speech
Mr Alexandre Jollien, Philosopher (Switzerland)

ANNEXE B

Programme

Mercredi 5 février

15h00 : **Cérémonie d'ouverture**

Orateurs :
M. Alvaro Gil-Robles, Commissaire aux Droits de l'Homme du Conseil de l'Europe
M. Lars Loekke Rasmussen, Ministre de l'Intérieur et de la Santé du Danemark
Invité de marque : *M. Paulo Coehlo*, écrivain
M. Andres Lehtmets, premier Vice-Président du Comité européen pour la prévention de la torture et des peines ou traitements inhumains ou dégradants (CPT)
Dr Marc Danzon, Directeur régional du Bureau régional de l'OMS Europe

Jeudi 6 février

9h00 – 9h45 :
SESSION 1: **Santé mentale et droits de l'Homme**

Orateurs:
Prof Stephen Marks, Directeur, Centre François Xavier-Bagnoud, Harvard School of Public Health, Etats-Unis; et
Lord Alderdice, Président de l'Assemblée de l'Irlande du Nord
Intervenant:
M. John Henderson, Santé Mentale Europe

Cette session sera consacrée à la relation entre « santé mentale » et « droits de l'Homme » et à définir la santé mentale comme étant un aspect du droit à la santé. Le préambule de la Constitution de l'OMS conceptualise la santé comme étant « un état de complet bien-être physique, mental et social, et ne consiste pas seulement en une absence de maladie ou d'infirmité ». L'expression « personnes ayant des problèmes de santé mentale » s'utilise de façon courante, couvre diverses situations, mais n'inclut en aucune façon la difficulté de s'adapter aux valeurs morales, sociales, politiques ou autres. Selon les circonstances trouver un juste équilibre entre le droit à la santé et au traitement ou le droit à la liberté et à l'intégrité peut s'avérer difficile.

10h15 – 12h15
SESSION 2: **Restrictions à la liberté : procédures et critères pour le placement et le traitement involontaires et non-volontaires**

Oratrice:
Mlle Orsolya Szekely, juriste, Cour européenne de droits de l'homme
Intervenant:
M. Lars Jacobsson, Département de psychiatrie, Université d'Umeå, Suède

Grand nombre de personnes, y compris des mineurs ayant des problèmes de santé mentale sont sujets au placement et /ou traitement involontaire ou non-volontaire. Ceci constitue une atteinte à la liberté physique de la personne concernée. Les lois et les règlements sur les critères et les procédures pour les placements et traitements involontaires et non-volontaires, leur révision ou interruption doivent garantir le respect des droits de la personne concernée, surtout à l'aune des exigences de la Cour européenne des Droits de l'Homme, de la Convention sur les Droits de l'Homme et la biomédecine et des normes du CPT. Aussi, le Livre Blanc aborde des questions importantes devant être discuter. La situation des groupes vulnérables tels les enfants et les personnes âgées mérite une attention toute particulière.

13h30 – 16h30
SESSION 3: **Intégrité et dignité**

Oratrice:
Prof. Hilary Brown, Canterbury Christ Church University, Grande-Bretagne
Intervenant:
M. Karl Bach Jensen, World Network of Users and Survivors of Psychiatry

Une fois que la personne ayant des problèmes de santé mentale est placée /ou traitée involontairement, elle se trouve souvent dans une situation de risque, ses droits pouvant être menacés. Les questions suivantes devraient par conséquent être abordées : son consentement au traitement ou au placement, la tutelle, le respect de sa vie privée, les mauvais traitements éventuels et les conditions de vie en général. Dans plusieurs pays, il existe encore de grandes institutions résidentielles pour personnes ayant des problèmes de santé mentale où les conditions sont sujettes à critiques. Encore une fois, la situation des enfants, des personnes âgées et autres groupes vulnérables mérite une attention toute particulière. Le Livre Blanc et les remarques faites par le CPT dans la partie III de son huitième rapport général représentent également des sujets importants.

Vendredi 7 février

9h – 12h
SESSION 4: **Egalité, non-discrimination et justice sociale: emploi, éducation, soins médicaux, sécurité sociale**

Orateur :
M. Lars Lööw, Ombudsman pour les personnes handicapées, Suède
Intervenant :
Prof Arthur Crisp, Directeur de Changing Minds Campaign, Royal College of Psychiatrists, Grande-Bretagne

Leur égalité, leur intégration, leur pleine citoyenneté ainsi que le droit de choisir de ces personnes doivent être promus et implantés. De même, certains domaines de la vie courante, tels la participation active dans la société, l'accès à l'éducation, la sécurité sociale, les soins médicaux et l'emploi méritent une attention particulière. Il importe en outre de souligner la nécessité de répondre, de s'adapter aux besoins des personnes ayant des problèmes de santé mentale. En matière d'égal accès aux droits de ces personnes, l'emphase ne doit pas être mise outre mesure sur l'égalité du traitement mais plutôt sur le résultat d'une action ou d'une omission. Au lieu de demander à ceux qui ont un handicap de s'adapter à la situation et à l'environnement des autres, il appartient à la société de prendre les dispositions nécessaires pour leur faciliter l'accès à la vie publique et privée. Les personnes ayant des problèmes de santé mentale ne doivent plus être perçues comme un problème mais plutôt comme des individus ayant des droits et représentant un atout pour la société, un gage de sa tolérance, de son pluralisme et de sa richesse, un outil favorable à son développement. L'article 15 de la Charte Sociale révisée et les Règles de l'ONU relatifs à l'égalité des chances revêtent un intérêt particulier. Les femmes, enfants, personnes appartenant à une minorité nationale ou ethnique et les personnes âgées qui ont des problèmes de santé mentale sont spécialement vulnérables. Ces personnes appartiennent à des groupes qui se voient souvent exposés à de la discrimination et/ou à des difficultés à faire respecter leurs droits indépendamment de leurs problèmes de santé mentale et, par conséquent, des risques de double discrimination peuvent être latents. Leur situation mérite d'être au cœur des débats.

13h30 –15h
SESSION 5: **Mise en application de / l'accès aux droits, la responsabilité, le contrôle et le lobbying: le rôle des gouvernements, les ONG et de la société civile**

Orateur :
Dr Athanassios Constantopolous, Centre pour la santé mentale, Grèce
Intervenant:
M. Klaus Lachwitz, Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e. V., Allemagne

Il faut encourager la ratification d'instruments internationaux pertinents, notamment, dans le contexte européen, la Charte Sociale révisée (article 15). Néanmoins, aucune loi, règle, politique n'est utile si elle n'est pas appliquée correctement. L'obligation conventionnelle internationale pèse sur les Etats. Afin de contrôler et de promouvoir l'application effective des droits des personnes ayant des problèmes de santé mentale, la possibilité de créer des organes spécifiques au sein de l'Etat doit être examinée, tout comme l'établissement d'un dialogue ouvert et la coopération avec la société civile, notamment les groupes d'utilisateurs, les ONG et les professionnels concernés. Les personnes ayant des problèmes de santé mentale sont souvent sujettes à des pratiques et attitudes discriminatoires dans quantité de domaines. Ceci est souvent attribuable à des lacunes au niveau de la sensibilisation des professionnels et de la population sur la nature même d'un problème de santé mentale. Les préjugés et inégalités structurelles et juridiques sont également à l'origine de cette situation. L'article 1 des Règles pour l'égalisation des chances des handicapés de l'ONU oblige les Etats à agir pour sensibiliser la société sur les droits, les besoins, le potentiel et la contribution des personnes ayant des problèmes de santé mentale. Les gouvernements et les ONG devraient coopérer en ce sens.

15h30-17h00
SESSION 6: **Conclusions**
M. Alvaro Gil-Robles, Commissaire aux Droits de l'Homme du Conseil de l'Europe
Discours de clôture
M. Alexandre Jollien, Philosophe (Suisse).

APPENDIX C / ANNEXE C

List of participants / Liste des participants

OPENING CEREMONY / CEREMONIE D'OUVERTURE
(5 February 2003 / 5 février 2003)

Mr. Alvaro GIL-ROBLES
Commissioner for Human Rights of the Council of Europe

Mr. Lars Loekke Rasmussen
Danish Minister for the Interior and Health

Mr. Paulo Coehlo
Author, Brazil

Dr. Andres Lehtmets
First vice-President of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)

Dr. Marc Danzon
Regional Director of WHO Regional Office for Europe

I. PARTICIPANTS

1. **Mrs. Susanne ABILD**
   Ministry of the Interior and Health, Denmark

2. **Lord John ALDERDICE**
   House of Lords, United Kingdom

3. **Ms. Monica ANTUNES**
   Literary agent for Paulo Coehlo, Spain

4. **Dr. Victor APARICIO BASAURI**
   Head of Services of the Mental Health Services, Spain

5. **Mrs. Begoñe ARIÑO**
   President of European Federation of Associations
   of Families of people with a Mental Illness

6. **Dr. Antonio BENTO**
   MD (psychiatrist), Portugal

7. **Mrs. Anna BROCKMANN**
   Federal Ministry for Health and Social Security, Germany

8. **Prof. Hilary BROWN**
   Canterbury Christ Church University, UK

9. **Mrs. Niamh Ann CASEY NEVILLE**
   Secretariat of European Social Charter DGII
   Council of Europe

10. **Dr. Athanassios CONSTANTOPOULOS**
    Mental Health Centre, Greece

11. **Prof. Arthur CRISP**
    Director of Changing Minds Campaign,
    Royal College of Psychiatrists, UK

12. **Mr. Jonas DAHL**
    Legal Expert of RSMH, Sweden

13. **Mr. Dirk DEES**
    Senator / Representative, The Netherlands

14. **Dr. Marina ECONOMOU**
    Professor of Psychiatry,
    University of Athens, Greece

15. **Mr. Ivan FISER**
    Central Europe Researcher,
    International Secretariat of Amnesty International

16. **Mr. Gabor GOMBOS**
    European Network of (ex)Users and Survivors of Psychiatry

17. **Mr. Hermann HAACK**
    Commissioner of the Federal Government
    for Matters relating to Disabled people, Germany

18. **Dr. John H. HENDERSON**
    Mental Health Europe

19. **Mr. Marton HILLIER**
    Expert of the Ministry of Health,
    Social and Family Affairs, Hungary

20. **Prof. Lars JACOBSSON**
    Department of Psychiatry of Umeå University, Sweden

21. **Mr. Jan JARAB**
    Government Commissioner for Human Rights,
    Office of Government of Czech Republic

22. **Mr. Karl Bach JENSEN**
    Consultant
    Boardmember of World Network
    Of Users and Survivors of Psychiatry

23. **Mr. Alexandre JOLLIEN**
    Philosopher, Switzerland

24. **Ms. Irma KIIKKALA**
    Development Manager,
    National Research and Development
    Centre for Welfare and Health, Finland

25. **Prof. David KINGDON**
    Mental Health Care Delivery,
    University of Southampton, UK

26. **Prof. Valeriy KRASNOV**
    Moscow Research Institute of
    Psychiatry of the Ministry of Health, Russia

27. **Mr. Klaus LACHWITZ**
    Bundesvereinigung Lebenshilfe fur Menschen
    Mit geistiger Behinderung e.V., Germany

28. **Dr. Andres LEHTMETS**
    First Vice-President of the European Committee
    for the Prevention of Torture, (CPT)

29. **Mrs. Ieva LEIMANE**
    Deputy Director to the Latvian Centre for HR and Ethnic Studies
    Program Director to the Mental Disability Advocacy Program

30. **Mr. Oliver LEWIS**
Legal Director
Mental Disability Advocacy Centre

31. **Mrs. Ingrid LYCKE ELLINGSEN**
Psychiatrist
European Committee for the Prevention of Torture (CPT)

32. **Prof. Stephen P. MARKS**
Director, François-Xavier Bagnoud Center
Harvard School of Public Health, USA

33. **Mrs. Marie-Hélene MATHIEU**
Holy See Observer

34. **Mrs. Leen MEULENBERGS**
Expert of the Federal Public Service of Health
Food Chain Safety and Environment, Belgium

35. **Dr. Michael MULCAHY**
Department of Health, Ireland

36. **Mrs. Antoaneta NENKOVA**
Children in Institutions Project
Bulgarian Helsinki Committee

37. **Mr. Jens OLSEN**
Senior Legal Adviser
The Danish Parliamentary Ombudsman's Office

38. **Mr. Pierre PERRIN**
Chief Medical Officer
International Committee of the Red Cross

39. **Mrs. Karin Munk PETERSEN**
Head of Section
The Department of Social Affairs, Denmark

40. **Mrs. Ruth REUSSER**
Director, Federal Office of the Justice, Switzerland

41. **Dr. Helena SILFVERHIELM**
Medical Adviser,
National Board of Health and Welfare, Sweden

42. **Mr. Claes Göran STEFANSSON**
National Board of Health and Welfare, Sweden

43. **Mrs. Maria Luisa SILVA**
Analysis Unit Leader
Research and Right to Development Branch
Office of the United Nations High Commissioner for Human Rights

44. **Ms. Orsolya SZEKELY**
Lawyer, European Court of Human Rights

II. WHO REGIONAL OFFICE FOR EUROPE

Dr. Marc DANZON
Regional Director

Dr. Gudjon MAGNUSSON
Director, Division of Technical Support I
Reducing Disease Burden

Dr. Wolfgang RUTZ
Regional Adviser, Mental Health

Dr. Liliana URBINA
Desk Officer, Mental Health

III. COMMISSIONER FOR HUMAN RIGHTS OF COUNCIL OF EUROPE

Mr. Alvaro GIL-ROBLES

IV. OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS

Mr. Fernando MORA
Mr. John DALHUISEN
Ms. Anja SNELLMAN
Mrs. Christine GIGANT

V. INTERPRETERS

Mrs. Marie-Claire BERTHELSEN
Mr. Noël PIAT