Mental disability law in central and eastern Europe: paper, practice, promise

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This paper explores socio-legal issues within mental disability systems in central and eastern Europe, focusing on the ten countries which have entered into an accession partnership with the European Union (EU) and will become members within the next few years, namely (starting from the north): Estonia, Latvia, Lithuania, Poland, Czech Republic, Slovakia, Hungary, Slovenia, Romania and Bulgaria, countries with a combined population of almost 100 million people. These EU accession countries share a recent history of either being parts of the Soviet Union (Estonia, Latvia, Lithuania), part of the Socialist Republic of Yugoslavia (Slovenia) or ruled from communist Moscow (the others).

To assert that these countries share the same political, social, cultural, linguistic or economic situation, would be as foolish as to think that countries in western Europe can be thought of in the same manner. For example, Bulgaria's gross domestic product per head is around six times lower than Slovenia's. Notwithstanding the near-impossibility of making broad-brush statements about "the region" (as I will refer to these countries), and whilst this paper does not attempt to be an academic comparative analysis or a comparison with (better?) mental disability systems in other parts of the world, what follows will attempt to draw out important themes in mental disability law and practice. The sources of information presented here come from a combination of site visits by the author in all 10 countries to institutions delivering services to people with mental disabilities,³ interviews with users and ex-users of mental health services, with lawyers, psychiatrists and other professionals, and from delivering human rights training seminars in each of the countries with support from the

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¹ It is envisaged that eight countries will join the EU in May 2004, whilst Romania and Bulgaria have been told that 2007 is the indicative date for their accession.

² For more on EU enlargement, sewww.europa.eu.int/comm/enlargement/index.htm

³ Institutions visited include psychiatric hospitals, long stay institutions (otherwise known as social care homes) for adults and children, children's hospitals, prisons and day care centres.

Council of Europe.⁴ Facts presented here as a pastiche are either first hand testimony, or have appeared in writing elsewhere and are therefore referenced. Whilst I will not refrain from describing systemic violations of basic human rights in all of the countries mentioned above, I would like to emphasize the immense dedication and warmth of many staff members, working with limited resources in institutions which vary from the basic to places unfit for human habitation. A note on terminology: "mental disabilities" is used here to refer to children and adults who have been diagnosed as having mental health problems ("mental illness") and/or intellectual disabilities.⁵

The main source of law in the accession countries is each country's Constitution, which usually specifies the inherent and inalienable dignity of the person, the right to life, the right to be free from torture, inhuman and degrading treatment, and the (limited) right to liberty. Crucially, most Constitutions provide that binding international law shall be respected by courts, and in some cases, shall take precedence over domestic law.⁶ All of the EU accession countries have ratified the European Convention on Human Rights (ECHR), so Convention points can – theoretically at least – be argued in domestic courts, in a similar fashion to the situation now in England and Wales, and cases can be taken to the European Court of Human Rights in Strasbourg. However, it is rare for lawyers to raise ECHR points domestically, partly because human rights training in law schools is new, and partly for the fear that judges will not know what to do with international legal arguments. All countries in the region now have specific post-communist mental health legislation, whose compliance with the ECHR.⁷ and international "soft law" varies enormously.

A note on the recent historical context. During the holocaust thousands of adults and children with mental health problems and intellectual disabilities were sterilized, tortured and murdered by the Nazi regime. Appalling human rights abuses continued during the soviet/communist era. For half a century hundreds of remote and closed institutions were built across the region, satisfying the socialist ideology of making non-"normal" people disappear, which meant isolating people with mental disabilities, and fuelling prejudices and discrimination against them. Such institutions ranged from army barracks to architecturally stunning nationalized nineteenth century aristocratic homes. Rarely were institutions built for the purpose of providing specialized care. The practice of detaining people in such institutions for political reasons during the communist times has been well documented, but for each political prisoner there were hundreds of people with mental disabilities languishing in the same institutional regime and suffering the same discipline and abuse. Countries in the region therefore have inherited a mental health service which has for 50 years been based in institutions where things that happened inside were largely unknown. The majority of the institutions used during the communist regime are still in operation. Due to monetary cut-backs in most countries' health and social care budgets, some people endure worse conditions now than they did at the fall of communism.9

- 4 For more information see www.mdac.info
- 5 For a review of the special problems faced by people with intellectual disabilities, see the 2002 reports produced on some of the accession countries by Inclusion Europe, available at www.inclusion-europe.org
- 6 For texts of many constitutions, see http://www.uniwuerzburg.de/law/
- 7 For a review of ECHR and mental disability, see Lewis, O., "Protecting the rights of people with mental disabilities: the European Convention on Human
- Rights", (2002) European Journal of Health Law 9(4), 293–321
- 8 Such as the Principles for the Protection of Persons with Mental Illness, adopted by the United Nations General Assembly resolution 46/119 of 17 December 1991, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the UN General Assembly in 1993 (A/RES/48/96)
- 9 See Hayward, R. and Nica, R. Gaining Ground, Hamlet Trust 2000 www.hamlet-trust.org.uk

Detention

Psychiatric detention under Article 5 of the ECHR is regulated in all countries by domestic mental health legislation. The legislation usually provides for a detention of a person with mental disability of such nature or degree that s/he needs to be detained and treated as an inpatient. Emergency procedures which provide fewer safeguards are more frequently used than non-emergency routes. There are concerns across the region of the lax entry criteria into involuntary detention, so that someone can be detained and involuntarily treated by the decision of a single doctor, on the say of an irritated family member. The heavy-handedness of police officers taking people from their homes is cause for concern. ¹⁰ In some countries prosecutors still enjoy the Stalin-esque power to order detention in a psychiatric institution without a prior medical opinion. Thanks to successful Strasbourg litigation against Bulgaria the government have conceded that the legislation must be amended. ¹¹

When people are detained information is scarce. There are no national information leaflets or posters in any of the countries. Testimony from users/survivors indicates that verbal explanations are rarely given by staff, and if they are given, are inadequate. In Latvia, for example, it is the practice for patients not to be informed about their diagnosis, treatment or prognosis; for fear that this would increase the stigma in society against people with mental disabilities. In many countries psychiatrists and nurses do not share the opinion that information provision is therapeutic in itself, and either are not aware of, or do not follow, provisions in domestic legislation, or Article 5(2) of the ECHR. In most countries (and this is no surprise) there is a hazy distinction between those detained compulsorily and voluntary patients. So-called voluntary patients are sometimes forced to sign admission papers under coercion. Patients remain largely unaware of their legal status and unaware of their legal rights, unequipped to raise concerns about their detention or treatment. Patients' advocates in hospitals are uncommon, as are adequate complaint mechanisms within institutions and inspectorate bodies to supervise and monitor conditions and treatment.

Court review of detention

After a person has been detained by a psychiatrist, most countries' legislation provide for a review by a judge, as required by Article 5(4) ECHR, which provides that "[e]veryone who is deprived of his liberty [...] shall be entitled to take proceedings by which the lawfulness of detention shall be decided speedily by a court and his release ordered if the detention is not lawful". However, no country in the region is in compliance with Article 5(4). In Estonia, the psychiatrist sends the judge a psychiatric opinion, and the judge decides on the case "without a hearing" (the patient playing no part in the proceedings). In Slovakia, the judge sends a rapporteur to the hospital who interviews the psychiatrist and the patient, reporting back to the judge who makes the decision. In Lithuania, the hospital either sends a fax to the court, or the psychiatrist personally goes to the

¹⁰ See International Helsinki Federation, Human Rights in the OSCE Region Report 2002, p.118 on Estonia

¹¹ See Varbanov v. Bulgaria, Application no. 31365/96, judgment 5 October 2000. Also Amnesty International (2002) Bulgaria: Far from the Eyes of Society, AI Index: EUR 15/005/2002, p.16

¹² Personal communication with psychiatrists, Latvia, May 2002.

¹³ Section 13(4) Estonian Mental Health Act 1997

¹⁴ Personal communication with psychiatrists and user/survivors during a visit to Slovakia, May 2002.

court (without the patient) to ask for a court decision regarding detention. 15 In Poland, the judge visits the hospital and speaks with the psychiatrist and (sometimes) with the patient, but no representative is provided. 16 In Hungary, there are court hearings at the hospital, where patients are provided with legal representation. However, patients rarely know who the people are in the room, the patient's representative routinely does not meet the patient before the hearing, and hearings commonly take less than five minutes.¹⁷ In those countries where there is a hearing of sorts, it is common for the patient not to be afforded (in Strasbourg language) "equality of arms", that is, to be on an equal footing with the detaining authority so that the patient can fairly test the lawfulness of detention. Medical records and psychiatric reports are rarely disclosed. Lawyers act in a manner which would be regarded by many as unethical and negligent. Lawyers do not meet clients before the hearing and by they make representations to the court not based on client's instructions, but on the lawyer's interpretation of what is in the client's "best interests". The lack of legal and judicial training in human rights as a whole and mental disability law more particularly results in lawyers and judges being role-less. The participation of judges and lawyers in review of mental disability detention is not so much a procedural safeguard, but a passive presence in a rubberstamping exercise. 18 Article 5(4) ECHR rights are largely observed on paper across the region, but an examination of the practice reveals many violations of international law.

In all jurisdictions the court review takes place after a very short period of time after compulsory admission. In Hungary for example the hospital must notify the court within 24 hours of admission, and the court must make a decision within the next 72 hours. If the hearings were meaningful (which they are not) a court review of detention within a week of admission (if the patient and the lawyer act quickly to prepare the case) is clearly beneficial to those who feel their detention is unjustified system. Having said that, the hearing would be more like a bail hearing than a full trial.

Owing to pressure from state health insurance systems in the region, people detained in psychiatric hospitals are held under compulsion for a remarkably short period compared with other jurisdictions. The state pays for the bed at a lower rate after a specified length of inpatient stay (anything from 20 to 60 days). Patients are therefore routinely treated with high doses of medication, then discharged, sometimes of course still suffering from acute mental health problems. It is virtually unheard of for a person to be civilly detained (under the equivalent of a section 3 of the English and Welsh Mental Health Act 1983) for more than two months. Query whether the difference between practice reveals more about the tendency by English and Welsh psychiatrists to be cautious when making discharge decisions than it does about psychiatric speediness in central and eastern Europe.

¹⁵ Personal communication with psychiatrists, a director of a psychiatric hospital and users and ex-users of psychiatric services, Lithuania, June 2002.

¹⁶ Personal communication with psychiatrists, lawyers and user/survivors, Poland, September 2002.

¹⁷ Mental Disability Advocacy Center, (2003) Liberty Denied: mental disability detention in Hungary (forthcoming)

¹⁸ For more on the role of lawyers in court hearings under Article 5(4) European Convention on Human Rights, see Lewis (2002), op cit.

Forensic detention

More worrying from a length-of-detention point of view is detention via the criminal courts. Those who are found not criminally responsible for criminal offences are sent to high security hospitals. In some countries these are so-called hospitals within prison confines (Hungary); in others on locked wards of psychiatric hospitals (Czech Republic); in others, open long stay-homes for people with mental disabilities (Slovakia). In most jurisdictions in the region, as in the UK, the criminal court sentences the patient-offender for an indefinite period of detention and treatment. Detention is reviewed in most jurisdictions annually, but patients in some countries (eg. Poland) have no opportunity to participate in the process, as the judge decides on papers sent by the treating psychiatrist and an "independent" psychiatrist (who may be employed by the same institution).

In Hungary, the equivalent of an English mental health review tribunal hearing for a "restricted" patient takes place annually at the Budapest criminal court. Proceedings are over in less than 5 minutes, and the issues remain untested: similar to detention hearings under civil law, lawyers do not meet their clients or take instructions. Forensic patients across the region are detained at the will of psychiatrists and do not have adequate access to a court, contrary to Article 5(4) ECHR. Mental disability hearings have been overlooked by the many judicial training seminars focusing on criminal law organized by international organizations. International studies have been conducted on court-appointed lawyers in criminal proceedings, but not in mental disability hearings.

Social care homes

Hundreds of thousands of people with mental health problems, intellectual disabilities, alcohol problems, drug addiction (and people with no health problems at all, so-called "social cases") are housed together in what have become known as "social care homes". These are large residential institutions which house any number between around thirty and over 700 residents. Pesidents are rarely discharged. Apart from Hungary and Bulgaria, the human rights torch has not shone inside social care homes. Social care homes are both geographically and metaphorically far from the common consciousness. They usually fall within the responsibility of the ministry of social affairs – not health – which makes them politically more mundane. In violation of international standards, social care homes remain the breeding ground of human rights abuses and their residents the overlooked victims of systemic ill-treatment, degradation and boredom until death. In some cases social care homes are the very cause of death.

These institutions contain mostly overcrowded bedrooms, some devoid of bedside cabinets, wardrobes or any kind of visual stimulation. In some homes residents share clothes, in others they are dressed in old military uniforms to save money. In some homes residents share toothbrushes if they are provided with any form of dental care at all. Many residents have no teeth: the result of dental care neglect and inadequate diet. Washing ranges from a single shower in an unheated room

- 19 It is believed that the largest social care home in the region is in south west Hungary.
- 20 Although the Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has visited social care homes in Estonia (unpublished), Slovak Republic, Hungary, Romania and Bulgaria (see www.cpt.coe.int), only Hungary and Bulgaria have received international NGO focus see Mental Disability Rights International Mental
- Disability and Human Rights: Hungary (1997 and 2003) www.mdri.org, Mental Disability Advocacy Center (2003) www.mdac.info, Amnesty International (2002) op cit
- 21 See Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) "Substantive Sections", available from www.cpt.coe.int

(which means that residents are unable to wash regularly in the winter), to mass bathing in front of staff and other residents. In some institutions toilets have no divisions between them, and in others toilets consist of a hole in the ground in the garden, forcing residents to defecate in their bedrooms.

Food is served usually in a central dining room *en masse*. There is no choice in the menu, and as a result of mass catering and budget constrictions, food in some institutions in some countries consists of "soup". In some institutions there is no need for a knife and fork, for the dual reasons that the residents do not have teeth, and because nothing other than liquid is served. Residents in some institutions eat from metal spoons and metal bowls for every meal.

Residents of social care homes are subject to arbitrary detention. Although social care homes are not places where people are detained by law, *de facto* detention can take a number of forms: residents are not allowed out during first month; residents are allowed out on certain days of the week; residents are not allowed to go to church (too disruptive); residents have to seek the permission of the director to leave – even to go to the local shops. In a study on all of Hungary's 52 social care homes, researchers found that liberty was restricted in all of them.²²

The right to sexual relations is restricted, and in some institutions people are punished for making consensual attempts. It is not unknown for married couples to be separated. In single sex social care homes, there is an even greater taboo surrounding same-sex relationships than in the wider community. The right to communicate with the outside world is often restricted, with permission having to be sought from staff to make telephone calls. In some institutions, staff enquire into the nature of the conversations before a resident is allowed to make a call. If the resident is under guardianship (see below) and the guardian does not agree to the resident making phone calls, this decision is enforced by the institution. Relatives or friends of residents who want to visit the institution are sometimes forced to visit within certain times on certain days. Bearing in mind the remote locations of institutions, restrictive visiting times may constitute an unjustifiable infringement on communication.

Staff

Psychiatric hospitals are chronically understaffed, as nurses leave poorly-paid jobs in search for employment in other areas. There are also chronic staff shortages in social care homes for adults and children across the region. During the night there are often perilously few staff on duty, forcing residents to intervene (restraining a fellow resident, for example, if that person becomes agitated). Staff are under-qualified and there is rarely any pre-employment screening. Once in the job staff rarely receive ongoing training. The shortage or lack of professionals trained in nursing, social work, psychology, occupational therapy, art therapy, speech therapy, as well as educationalists (sometimes called "defectologists") seriously undermine effective psycho-social rehabilitative care and treatment. As the European Committee for the Prevention of Torture has pointed out, "greater emphasis on social therapy would have a considerable impact upon the quality of care. In particular, [it] would lead to the emergence of a therapeutic milieu less centered on drug-based therapy and physical treatments".²³

²² Gombos, G., Kismõdi, E., Petõ, K., The human rights of patients in social care homes for the mentally ill

⁽Budapest, Hungarian Mental Health Interest Forum, September 2001).

²³ See para.43, CPT "Substantive Sections", op cit

Treatment

In social care homes, psychiatrists tend to visit every week or every two weeks. In large institutions patients can go un-assessed for years. In the majority of homes patients are overly medicated: it is not uncommon for residents with intellectual disabilities without a concurrent mental illness to be prescribed strong anti-psychotics in order to curb "challenging behaviour" which otherwise would be unmanageable by the few staff. Residents with mental health problems are routinely overmedicated using old anti-psychotic medication – classic side-effects are obvious even to medically untrained visitors. People suffering from alcoholism sometimes receive no treatment, and are punished when they drink. In short, care and treatment in social care homes sometimes amounts to no more than medication, television and a bed.

Consent to treatment is routinely ignored – medical paternalism rules across the region, not just in psychiatry. In some parts of the region, notably Bulgaria and Romania, electro-convulsive therapy is sometimes given in its barbaric "unmodified" form, that is, without anaesthesia or muscle relaxants, and/or given in front of other patients, contrary to international medical and human rights standards.²⁴ There are credible reports that clinical drugs trials on people in psychiatric hospitals proceed without adequate ethical scrutiny, leaving underpaid doctors open to accept money for providing "subjects". Free and informed consent in clinical trials is often lacking.

Restraint and seclusion

The use of (physical and chemical) restraint and seclusion in social care homes and psychiatric hospitals is cause for concern. Throughout the region instruments of physical restraint are used—fixation to a hospital bed with leather straps, tying a person to a chair using a bed sheet, restraint using a straightjacket. Sometimes there is no clear policy about when restraint can be used, patients remain un-monitored, and instances of restraint are not documented. Similarly, seclusion is used in some institutions, but others—particularly old buildings which were never designed as hospitals—there is no seclusion room, forcing staff to resort to restraints. Both restraints²⁵ and seclusion²⁶ are sometimes used as punishment. Sometimes chemical restraints are used instead of or as well as physical restraints.

In Hungary, Slovakia, the Czech Republic and Slovenia "caged-beds" are used in hospitals and social care homes. Caged-beds have been described as "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."²⁷ In some cases people are placed in a caged-bed if they become agitated. The author observed the long-term use of caged beds in one Slovak home:²⁸ seven women were each placed in a caged-bed for most of the day. The reasons given for using a cage bed on a 21-year-old woman

²⁴ See para.39, CPT "Substantive Sections" op cit. Also Inpatient psychiatric care in Bulgaria and human rights (Sofia, Bulgarian Helsinki Committee, 2001)

²⁵ Amnesty International (2002) op cit. p.44

²⁶ For example, in some Hungarian social care homes if a person has broken the house rules of the institution, the individual may be forced to undergo a lengthy period in seclusion. (source: personal communication with staff members and residents in two social care homes)

²⁷ Mental Disability Rights International (1997) op cit

²⁸ Personal communication at Ve_k_ Biel social care home, Slovak Republic. This social care home has been visited by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. See the report to the Government of the Slovak Republic on the visit to Slovakia carried out by the CPT from 9 to 18 October 2000 (CPT/Inf (2001) 29), available at www.cpt.coe.int

with intellectual disabilities was that "she is aggressive". When asked whether it was surprising that a person caged for long periods of time would become aggressive, staff maintained that in any case she was easier to handle. The reason given for another woman's placement in a cage bed was that she had high blood pressure: "she might fall out of bed." Arguments based on lack-of-resources are used by staff as an attempt (unwittingly?) to excuse and rationalize human rights violations. In its response to international criticism on the use of caged-beds, the Slovak government stated that their use was necessary because of staffing shortages. Given that there can be no justification for torture, inhuman or degrading treatment or punishment under international law, the government itself has provided the solution for their eradication: employ more staff.²⁹

Caged-beds do result not merely in ill-treatment which in some cases verges on torture, but also tragedy. In November 2000 a man in a caged-bed in a Hungarian social care home was trapped during a fire: staff were not present in his room, his caged-bed was locked, there were no fire alarms. He died from major burns and smoke inhalation. In violation of the procedural requirements under Article 2 of the ECHR, there has been no adequate investigation of his death. Research recently conducted by Amnesty International in Bulgaria has revealed the worst human rights abuses in the region. In 2001 Amnesty International documented women locked in a cage outside one institution. The cage was full of urine and feces and the women covered in filth. One woman was unclothed on the lower half of her body and many sores were visible on her skin.³⁰ In a move welcomed by disability rights activists across the world, Amnesty International has now included within its work the human rights of people with a mental disability. In its first major report in this field released in October 2002 on Bulgaria, severe and systemic abuses are reported.³¹

Guardianship

The lives of thousands of people in the region are affected in a fundamental way by guardianship. Regulated by Civil Codes largely unchanged since Soviet times, guardianship attracts a low priority for legislators pressed by the international community to reform more visible areas of the legal system. Pivotal in the whole mental disability system in central and eastern Europe, human rights abuses pervade guardianship: from judicial enquiry into incapacity, appointment of the guardian, the guardian's powers, oversight of the guardian and review of necessity of guardianship. ³²

Families commonly ask the court to declare their relative incompetent because of financial reasons: "I want to sell his summer house", said a relative in a court hearing observed in Estonia.³³ If a person has no relatives the State applies for guardianship, and if granted, a local authority, or a so-called "professional" guardian is appointed as guardian. The person whose capacity is in question is sometimes not informed of the application against them. Commonly the person whose capacity is in question is not legally represented. When there is a court hearing the doctor is given the power to advise the judge that the person's presence is not required. Sometimes there is a court-appointed representative who rarely meets or takes instructions from the client. There are often no live witnesses, and similar to detention cases, a brief written psychiatric opinion is accepted as unquestionable scientific truth. Sometimes the person now under guardianship is not informed of

- 29 See the response of the government of the Slovak Republic to the CPT report (op cit), (CPT/Inf (2001) 30), available at www.cpt.coe.int
- 30 Amnesty International press release "Bulgaria: Disabled women condemned to 'slow death'", AI-index:

EUR 15/002/2001

- 31 Amnesty International (2002), op cit
- 32 Mental Disability Advocacy Center (2003) op cit
- 33 Tallinn City Court, November 2001.

the court's decision. In most jurisdictions the legal test of incapacity is not defined in law thus few applications for guardianship are refused. In some countries a person can be involuntarily detained in an institution to assess his capacity.

Conflicts of interests are common where a family member is appointed as guardian and has control over finances. Different issues arise where directors or staff of institutions are the guardian of residents. If no family member is willing to be guardian, the guardianship office (an administrative body) will appoint someone who is paid per person under his or her control. In many countries there is a pool of "professional" guardians, who are often the guardian of more than 100 people.³⁴

The powers of guardians across the region are immense. The State often divests its responsibility to protect its most vulnerable citizens by handing a bundle of personal rights to one individual. A guardian can decide where the individual should live. In practice, this means that a guardian can force placement into a social care home, and can block discharge. A guardian sometimes has the authority to decide when a person can leave an institution, for example to visit friends or family on the weekend. Crucially, guardians control the individual's finances. They are often given the unchecked authority to sell real estate and personal possessions; sole access to bank accounts; disposal of old-age or disability pension.

In some countries, a guardian consents to or overrides refusal of medical (including psychiatric) treatment. In the example given above, the 21-year-old Slovak woman's father, who is also her guardian, approved her placement in the social care home and also the use of the caged-bed.

In many countries, the fact that someone has been deemed incapable means that s/he is stripped of legal personality. Access to a lawyer is therefore restricted, as the lawyer will not get paid. Access to a court is impossible, as the person is no longer deemed to be a person. In some countries, the Constitution blocks an "incapable" person from participating in elections and civic life, and takes away the person's right to have a national identity card, essential for interaction with a number of organs of the state.

Often the powers of the guardian are inadequately regulated. There is no duty on a guardian to meet with the person under guardianship or to take their (often capacitous) opinions into account when making decisions about that person's life. In most countries the local government's guardianship office is charged with the regulation of guardians, but frequently there is a lack of criteria for evaluating guardians, and a one-paragraph annual report blandly stating that "there were no problems this year" is adequate. Financial accounts are rarely checked. Only in Hungary is there a regular review of a person's status as incapable. In all other countries both the displacement of a guardian and the overturning of a judicial finding of incapacity are lengthy and difficult procedures. The issues within the guardianship system described here engage many articles of the ECHR, but remain under-reported and under-litigated.

Death

The numbers of deaths in some institutions is alarmingly high. When the Committee for the Prevention of Torture (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

³⁴ The author has met a person in Hungary who is the guardian to 158 individuals

in excess of 20% per annum.³⁵ 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.³⁶ Amnesty International's 2002 report reveals that records of deaths in Bulgarian social care homes are unreliable; post mortem examinations are rare, as are police investigations of suspicious deaths in social care homes.³⁷ Across the region "cardiac insufficiency" is commonly the official cause of death, even in young people with no previous heart abnormalities. Deaths from pneumonia and hypothermia in some psychiatric institutions in the winter are grossly disproportional to deaths from those causes outside institutions. There are no countries with adequate state machinery for questions to be posed, let alone answered in a manner compatible with the now stringent requirements of Article 2 ECHR – the right to life.

Promise?

Within the EU accession region there is an expectation that things will change after membership to the EU. Twelve years after the establishment of democracy, the locus of psychiatric and social care remains largely institutional. A growing network of non-governmental organizations providing innovative services based on the principles of inclusion, and constituting alternatives to long-term institutionalization, battle against some governments who are not moving forward with a strategy of closing of large institutions and establishing community-based psychiatric and social services. Governments are slow to realize that large institutions are morally and economically costly. In the meantime, children are given little state support and are segregated in special schools, whilst institutionalized children with intellectual disabilities, receiving inadequate education, leave children's homes to adult institutions. People with mental disabilities living in the community face profound difficulties in societies with few support-structures beyond those provided by the few non-governmental organizations. These difficulties include getting and holding down a job in the absence of regulations prohibiting discrimination in employment, with social security payments barely enough to survive.

The ECHR and international soft law standards are valuable weapons with which advocacy groups can campaign, but without political will to invest money in the right places, without diplomatic pressure from the EU and existing Member States, without intense domestic and international advocacy efforts, and without the willingness of professional groups to recognize the inherent value of respecting human rights, the prospect of change remains low. Rights and safeguards exist largely on paper. Governments appear to be satisfied to enact human rights compliant mental health legislation, whilst ignoring mechanisms to ensure enforcement of the law in practice. The lack of state legal aid systems, the problems of access-to-justice by those under guardianship housed in remote institutions, the few lawyers willing to represent people with mental disabilities, coupled with the unwillingness of domestic courts to hear ECHR points and the grinding slowness of the Strasbourg Court all combine to produce a pessimistic situation in which the realization of human rights seems a long way off. It is hoped that the non-governmental organizations such as the

³⁵ CPT report on 1995 visit to Romania, published 19 February 1998, (ref CPT/Inf (98)5)

³⁶ CPT report on 1997 visit to Bulgaria, published 28 January 2002, (ref CPT/Inf (2002)1)

³⁷ Amnesty International (2002), op cit

³⁸ For networks of NGOs in the region, see the Mental

Disability Advocacy Program www.osi.hu/mdap and Hamlet Trust www.hamlet-trust.org.uk

³⁹ World Bank (2000), Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union

regional Mental Disability Advocacy Center will assist lawyers and activists to improve the situation of people with mental disabilities across the region.

It is doubtful that the human rights of people with mental disabilities will be better respected once accession countries join the EU. With the exception of Turkey, human rights are not a key priority for the largely *economic* European Union, despite its mantra of "respecting the principles of liberty, democracy, respect for human rights and the rule of law". ⁴⁰ Although professing to take into account a country's human rights record prior to accession, the EU has already indicated that all central and eastern European candidate countries have ticked the necessary human rights boxes. The EU has failed to assert adequate pressure on accession countries to reform their mental health systems – perhaps, because mental health services are thought of purely as a health issue and not a human rights issue. Despite the efforts of inter-governmental and non-governmental organizations, the accession countries look set to become EU Member States whilst continuing to violate the most basic human rights of people with mental disabilities.