Thinking About the Rest of the World: Mental Health and Rights Outside the ‘First World’

PETER BARTLETT

I. Introduction

The considerable preponderance of literature relating to mental health law is framed in the context of economically advantaged countries, primarily in North America, Western Europe and Australia and New Zealand. These origins are reflected in a specific set of assumptions regarding mental health law. These assumptions in part relate to the nature of the legal subject. These are countries where modern legal forms flow from a broadly post-enlightenment mentality, where individual rights and liberties are the stuff of national identity. Rights to control civil confinement, or to control mandatory psychiatric treatment, have developed in these jurisdictions in the context of this broader legal culture.

The economic and cultural context also shapes the context of litigation in other ways. Extensive, politically developed and largely benevolent (if often paternalistic) psychiatric professions, coupled with increasingly active user groups, have made a significant impression on the form and organisation of services. Relative to other parts of the world, people with mental disorders in economically advantaged countries benefit from access to inpatient and outpatient specialist care of a comparatively high standard, availability of modern psychiatric treatments, and programmes of care, support, accommodation and

* While much of my understanding in this area has benefited from my work with the Mental Disability Advocacy Center (MDAC) in Budapest, including as a board member for that organisation, the views expressed are my own and do not necessarily reflect the views of that organisation (nor, of course, the University of Nottingham nor the Nottinghamshire Healthcare NHS Trust). I have further benefitted from involvement in a project to reform the mental health law in Lesotho, a project graciously funded by the Nuffield Foundation. My thanks to Rachel Jenkins of the Institute of Psychiatry, King’s College London, for providing generous comments on a draft of this chapter, and to the participants at the Prato workshop for their insights.
financial assistance within the community. The form and standards of all of these programmes are quite appropriately the subject of ongoing research, debate, complaint, and litigation. Nonetheless, the existence of these standards of care fundamentally affects the approach to and the context of litigation in these nations.

This developed economic and legal culture is in the background of many of the papers in this volume. Insofar as the authors in this volume question the appropriateness of ‘rights-based legalism’, it is in the context of societies where moves towards such legalism have been on the political agenda for decades. At least some of the mores of that legalism are already integrated at least to some degree into the practices of compulsion in psychiatry: anyone who was going to be amenable to a legalistic or human rights approach is already talking that talk, although not necessarily always walking that walk as much as we would like. The question in these developed countries is less likely to be ‘was all that ever a good idea’, than ‘have we achieved as much through this route as we can hope for’.

Outside this rather narrow band of developed countries, the situation is markedly different. Human rights as understood in developed countries, and in particular the human rights of persons with mental disabilities, are not as high on the political, justice, social or professional agendas. Social Services are grossly underfunded by the standards of developed countries, and have to operate in a context of far lower government expenditure on the health, educational and social sectors as a whole. Institutional standards may often be distressingly poor. In countries where large mental hospitals and other related institutions have been long established, such as those in central and eastern Europe, there is often little or no local experience of de-institutionalisation and transition from central institutions to local comprehensive care. Mental health legislation and regulation often ranges from the minimal to the non-existent. Frequently, such legislation as there is has become significantly out-dated. Certainly, there is often no history or tradition of legalism of the sort that developed ‘western’ nations now largely take for granted.

The questions to be addressed by this chapter are thus rather different to the others in this volume. It is not whether we have achieved as much as we could hope for, but rather is the rights-based endeavour worth promoting at all in such a markedly different resource, professional and cultural context? Or would people with mental disabilities in these countries be better served by some other form of reform agenda?

It will be clear from what follows that rights-based legalism is not enough on its own. At a minimum, provision of an appropriate infrastructure of services (however we wish to define ‘appropriate’), more direct involvement of users throughout the mental health system, and widespread challenges to stigma throughout these societies are also required. This will not be news to the readers of this volume from economically advantaged countries, as it reflects experience in the developed world over the last roughly 40 years. The question is not whether rights-based legalism is enough; it is instead whether it should be a part of the way forward.
II. Rights as a Model

If we are to discuss the desirability of ‘rights-based legalism’, it is of course necessary to define the field. At the beginning of the twenty-first century, rights may mean a wide variety of things. Within classic human rights, there are a variety of ‘fundamental’ rights, essentially to be free from state intervention: the right to liberty, the right to security of the person (sometimes taken to include a right to make decisions regarding medical treatment), the right to judicial processes and equality before the law, and the right to privacy, for example. Variations on these rights are contained in most post-enlightenment human rights instruments—the European Convention on Human Rights, the African Charter of Human and Peoples’ Rights, the Canadian Charter, the American Bill of Rights, and so forth. Most of these instruments currently offer some form of legal redress for individuals who consider that their rights under these instruments has been infringed. The issues of access to justice that have long been the stuff of socio-legal analysis are of course important limitations for potential litigants, but in most of the world, these rights are at least in theory enforceable.

Over the twentieth and early twenty-first centuries, human rights law has moved increasingly into rights of social participation, however. Some of these rights are also part of the traditional corpus—the right to vote, for example—but in recent decades the number and scope of these rights have been expanding. Rights to standards of services and standards of institutional care, and rights to health care are obvious examples. The recent United Nations Convention on the Rights of Persons with Disabilities, discussed elsewhere in this volume, provides a particularly broad array of these rights to participation. These rights can be interesting in the context of mental health law, as they change the way those involved in the system are grouped. For the classic legal rights, persons with mental health problems are often pressing their right against their treatment provider: civilly detained patients litigating for their freedom against their

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4 The Bill of Rights is the name by which the first 10 amendments to the Constitution of the United States of America are known. They entered into force on 15 December 1791.
5 United Nations Convention on the Rights of Persons with Disabilities, adopted 13 December 2006, GA Res 61/106. UN Doc A/Res/61/106 (entered into force 3 May 2008). See in particular rights to accessibility (art 9), freedom from exploitation (art 16); community living (19), education (art 24), health (art 25), habilitation and rehabilitation (art 26), work and employment (art 27), adequate standards of living and social protection (art 28); participation in public and political life (art 29), participation in cultural life, leisure activities and sport (art 30). See also Oliver Lewis, this volume, ch 5; Annegret Kämpp, this volume, ch 6 and Tina Minkowitz, this volume, ch 7.
treating psychiatrist, for example. Second generation rights, however, may instead be about systemic provision, and thus service providers and service users may be united on the same side. A service user litigating for better mental health services may well be supported by his or her treatment team, not litigating against them. The real target of such litigation may be those in government in charge of resource allocation.

Enforceability of these second generation rights by aggrieved individuals will depend on the instrument in which they are contained. Often, the most relevant rights (such as the right to health, and the right to community living) are circumscribed with language that limits the effect of the right, or are not directly enforceable by individuals. One way of engaging with the desirability of ‘rights-based legalism’, therefore, would be to ask whether substantive buttressing and more direct enforcement of these rights would be an appropriate way forward, since ‘rights-based legalism’ will be beneficial only if relevant rights are available for enforcement.

The trend in recent years has been to require that these rights are provided in a non-discriminatory fashion. Of particular relevance for current purposes, non-discrimination on the basis of disability has increasingly become a matter of legal and public policy. In developed countries, this has placed the law relating to people with mental disabilities in a new context. Justifications for legal interventions are no longer as clear as they once were—a topic for a different time, but an important topic nonetheless. For current purposes, the point is that in human rights law, the mere existence of a mental disability is no longer an obvious justification in itself for differential legal treatment, nor for the deprivation of rights. This is not of course to say that human rights law need be blind to different circumstances. Requirements to make ‘reasonable accommodation’ to accommodate the needs of persons with disabilities are an obvious example where consideration of difference is in itself a human rights requirement. Such concepts are generally intended to buttress the rights of affected individuals however, not to restrict them.

That may be taken as the broad structure of human rights. Any departure from these rights raises particular theoretical problems. By definition, these rights are meant to be universal: they are to apply to everybody, in all countries signing the relevant instrument. Allowing a ‘pick and mix’ approach to people who warrant human rights protection raises dangerous precedents within countries: if some groups do not warrant protection, why not others?

A considerable amount of debate regarding mental health law and service provision in developed nations has in recent years moved away from rights-based analysis. Even a number of papers in this volume seem to consider that the key rights issue is now optimising service provision and good outcomes, as defined by medical indicators. Questions of coercion become re-phrased to make them
appear human rights neutral. Expressly or by implication, the classic rights questions about whether people with mental disabilities should be permitted to refuse compulsion, or the development of firm and objective criteria for compulsion, are viewed as somehow old-fashioned, quaint, ‘SO 10 years ago’. Yet moves away from strong affirmations of human rights in our own countries undercut the credibility of human rights arguments abroad. In an international context, departures from universality also raise problems of credibility for the human rights project overall: how are we to pressure a nation known for human rights violations to comply with human rights instruments, if our own countries are themselves choosing to depart from those ‘universal’ norms when convenient to do so? Whether this is an appropriate approach for developed countries is outside the scope of this chapter, but for the sake of persons in other countries, both within the mental disability field and outside it, for whom fundamental rights have not been achieved and may have real import, this is not a position we should sleep-walk into.

The pursuit of these rights however implies a level of legalism. As noted above, access to courts for the determination of civil rights is itself a part of the human rights framework, and a move from it may itself imply a human rights violation. ‘Rights-based legalism’ may perhaps be taken to extend beyond the territory of traditional human rights, defined in international treaties and post-enlightenment national constitutions. In many countries, legal regulation of matters relating to mental disability extends into areas that are not necessarily pivotal to human rights as defined above, and these areas may at least in theory be subject to litigation. English law, for example, allows judicial challenge of a broad array of decisions made by a public authority, including the National Health Service, and occasionally litigation has arisen in a psychiatric context that does not raise obvious human rights issues. We have in recent years seen an application challenging an individual’s categorisation as ‘psychopathic’ rather than ‘mentally ill’, for example. These cases are very much the exception, however. English litigation in the mental health field is overwhelmingly about the scope of basic freedoms, in particular rights to liberty and freedom from involuntary treatment.

The arguments for rights-based legalism outside the classic human rights context are quite different than for fundamental human rights issues. Here, the arguments are likely to reflect skirmishes over power at a relatively specific level, the micro-theatres of power that make Foucauldeans salivate. A defence of rights-based legalism in this context might be based on the protection of some form of power to the individual, which might in turn be taken to protect some vestige of personal dignity. It might also be defended as a punitive/threatened

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7 R (on the application of B) v Ashworth Hospital Authority [2005] UKHL 20.
procedural ‘stick’ in the background, which practitioners will avoid by better engagement and communication with their patients/clients, an outcome that seems highly desirable. The fact that such disagreements do not engage with fundamental human rights thus does not necessarily mean a rights-based approach is inappropriate.

Indeed, the use of law as a structure to these debates opens a somewhat different view of human rights in mental health. Human rights, clearly in one sense, is a set of principles and standards to which everyone in society is entitled—a top-down vision defining how state action is restricted. But human rights can also be viewed from the bottom up—a way in which a framework is created for marginalised peoples to engage with (and to insist on engagement with) the decisions that affect them, either as groups or as individuals. Without that engagement, human rights law rather misses the point, since that engagement is fundamental to the dignity of individuals and peoples that human rights law presupposes. The right to refuse treatment is perhaps a helpful example. Certainly, the right to refuse treatment is important because of classic political doctrines concerning limitation of state power; but it is a reasonable speculation that this is not the key concern of many people with mental disabilities who want the right to refuse. Anecdotal evidence would suggest that few people with psychiatric disabilities want to refuse all medication or treatment. For them, the right to say ‘no’ is not about refusal of everything; it is about creating a long-stop that requires the treatment provider to engage with them about the decisions that will affect them. It is thus about articulation of the self, and about the individual claiming his or her own dignity. It is about the determination not simply to become a passive clinical object. This makes it about a very different vision of human rights, and perhaps the most important vision. Without this legal protection, the risk is that overworked clinicians use power as convenience, to reach the ‘right’ clinical decision.

In practice, litigation that is clearly outside the scope of human rights discourse is relatively rare. Much more frequent is litigation that, although taken by the domestic courts to be outside the scope of human rights law, nonetheless arguably engages human rights issues. In England in the last few years, for example, we have seen courts fail to find that the European Convention on Human Rights is engaged, let alone violated, in the cases, respectively, of an individual lacking capacity being institutionalised over the objection of competent family carers,8 and of a competent and objecting individual being given psychotropic medication.9 Human rights lawyers might see things rather differently from the courts in these cases, and, at least occasionally, Strasbourg has

8 Re S (Inherent Jurisdiction: Family Life) [2002] EWHC 2278 (Fam), esp at [39].
9 R (on the application of PS) v Responsible Medical Officer [2003] EWHC 2335 (Admin).
shared this different view.\footnote{Compare, for example, *R v Bournewood Community and Mental Health NHS Trust, ex parte L* [1999] 1 AC 458 to *HL v United Kingdom* [2005] 40 EHRR 761.} For these issues, the distinction between human rights and other rights-based legalism appears tenuous.

For purposes of the discussion that follows, the focus will be on decisions within this somewhat broader ambit of human rights, focusing on compulsory treatment, provision of services, institutional standards, detention, guardianship and other civil rights. From the discussion that follows, it will be clear that these issues appear to be relevant in central Europe and Africa, and they are included in international instruments of which the relevant countries are parties—most notably the European Convention on Human Rights and the African Charter on Human and Peoples’ Rights. Both of these treaties have courts to interpret their provisions, so in strategic terms, we can understand that we are talking not merely about rights as a discursive mechanism, but also a mechanism with some enforcement attached. For purposes of the distinctions drawn above, it will be taken that these generally engage with human rights issues. ‘Purely’ non-human rights related decisions, such as the categorisation question noted above, will not form a part of this discussion.

### III. What it’s Like In the Rest of the World

Basic demographic information regarding care in southern Africa and central Europe is contained in table 1. The first point that becomes obvious from that table is that ‘the rest of the world’ is not a homogenous place, and southern Africa is in many ways as different from central Europe as both are from economically privileged countries. Indeed, there is considerable variation between countries in each of these regions, and no doubt within countries themselves. Nonetheless, a few generalisations may be made.

#### A. Southern Africa

Much of Africa is, of course, chronically poor. It is not uncommon that average annual Gross Domestic Product (GDP) is less than US$1000 per person. It is an environment where often there have never been psychiatric services as would be recognisable to a western European. Overall health budgets are miniscule,
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sometimes as low as a few dollars per capita per year. Mental health budgets are in turn a small proportion of that, and are largely devoted to staff salaries and a small number of inpatient beds. In a number of southern African countries, there appears to be virtually no state investment in mental health services at all. In others, where figures were available, in most cases the mental health budget was less than two per cent of the health budget. Mental health tends to be under-funded in most countries of the world, relative to the impact of mental health on quality-adjusted life years (QuALYs); but these figures are extreme, particularly when placed in the context of tiny overall health budgets.

The result is minimal specialist service provision. According to the World Health Organization in 2005, there were no psychiatrists in either Angola or Malawi. Elsewhere, psychiatrists are exceptionally rare. Only in the Republic of South Africa (RSA) does the number exceed 0.5 per 100,000 population. Zambia, for example, has one psychiatrist in government practice for roughly 12 million people. Psychiatric nurses, social workers and psychologists are in similarly short supply. Kenya has 250 psychiatric nurses in the country, but the rate of production is far less than the rate of loss to retirement, mortality and brain drain (both overseas and internal). Indeed, in 2009, Kenya only produced one psychiatric nurse for the country.

This situation is further complicated by the physical size and geography of these countries. Outside the RSA, the average area per psychiatrist ranges from roughly 17,000 km² in Swaziland, to 342,000 km² in the Congo. To put that in context, the comparable number for Australia is 2600 km², for the United States of America, 230 km², and for France and the United Kingdom, 40 km² per psychiatrist. Averages in this context must of course be approached with care. In practice, mental health professionals, and psychiatrists in particular, are likely to be concentrated in urban areas. For these urban populations, specialist services will be considerably more accessible than for people outside these urban areas. For people in rural areas, the concentration of services in cities and the sparse coverage of primary care means that the nearest medical facilities may be a very long way away indeed, a difficulty exacerbated by limited public transport infrastructure.

Available treatments are limited. New generation antipsychotic drugs are unlikely to be available in the public sector, because of price. Training in new

\[^{11}\text{Statistics from the WHO in 2002 show for example that the per capita expenditure on health in Burundi was US}$3\text{ per year; in the Democratic Republic of the Congo US}$4\text{ per year; in the Central African Republic US}$11\text{ per year; and in Chad and Malawi, US}$14\text{ per year: World Health Organization, Global Health Atlas, available at: www.apps.who.int/globalatlas/}.\]


\[^{13}\text{World Health Organization, Mental Health Atlas (Geneva, WHO, 2005) also available online at: www.apps.who.int/globalatlas/default.asp. Since the WHO report, Malawi has successfully recruited a psychiatrist.}\]

\[^{14}\text{My thanks to Rachel Jenkins of the Institute of Psychiatry, King's College London, for this example.}\]
psychological therapies is limited and a shortage of specialists means that in any event, even where training is available, continuing supervision is difficult. Bed provision is similarly minimal, and such facilities as there are may be understaffed. The result is that facilities may be of poor quality. One African psychiatrist writes:

Most mental hospitals in Africa are located in the ‘economic ghettos’ of cities, and the forensic units are in turn located in the ‘ghettos’ of these hospitals, in locations often termed maximum security units. Though located in hospitals, these units are practically extensions of prisons, only worse because they exist as ‘orphan’ units that do not belong to either the medical or prison systems. In addition to the lack of adequate facilities, most countries have an average of one psychiatrist to a million. Those patients with the added need for forensic care have even less, and therefore for many people commitment to one of these units means a life sentence on a daily dose of chlorpromazine, carbamazepine and malnutrition.

A visit to many of these institutions leads to despair about the state of human rights and dignity in our continent. Those who are considered lucky are seen by a demoralized, poorly trained, and inadequately paid doctor who passes by the ward once every few weeks, to see only those patients who are most disturbed. For those who are of no trouble, there is no review.15

Formalised community support programmes are extremely rare, and indeed are logistically impractical on a national basis, when numbers of potential clients are compared with numbers of available specialist staff. Therefore there has long been recognition that in low-resource settings especially, but also in richer countries, involvement of primary care is crucial and integration of mental health into primary care is essential for population access to mental health care.16 While there can be little doubt that this is a desirable way forward, it is not an unproblematic strategy. Its drivers are at least partly a lack of professional and financial resources. While getting better use out of minimal resources is of course desirable, it should not detract attention from the other problem, that mental health is often significantly under-resourced in the region, with reference to overall health budgets.

While some family structures apparently continue to be strong, factors such as poverty, the journeying of breadwinners to seek employment and the death of potential carers (for example, from HIV) has made sustained family care increasingly problematic. Certainly, the anecdotal reports are that stigma against people with mental disabilities who return from institutional care is often entrenched, and sometimes violent.

The treatment picture is complicated by the existence of traditional healers, who are often the first port of call for the vast bulk of people who suffer from

mental health problems. There has been little research on the effectiveness of these treatments in terms of health and social outcomes. Harmful practices have been documented by some practitioners. Nonetheless, traditional healers are often well embedded in the community. They are seen to understand the cultural and community context, and as noted, are a reality in the care system. They do not necessarily work in opposition to the western-style psychiatrists. In Lesotho, for example, hospital workers have told me that traditional healers may often house a person released from hospital, and aid in their re-integration into the local community. Nonetheless, the framework of traditional healers can create complexities. It would seem that little if any research has been done as to how the remedies of these healers interact with the medications prescribed by physicians prescribing western medicines. Further, the cultural structure of the traditional approach can intersect awkwardly with western medicine. When a patient identifies his or her condition as flowing from demonic possession, for example, it may be difficult for a psychiatrist to determine how far this flows from psychosis, and how far from the fact that this is how the culture articulates some forms of mental condition.

The legislative framework in these countries is sometimes left over from colonial days. While some countries have produced new Acts, others have no legislative framework, leading to a lack of meaningful criteria for compulsory admission or compulsory treatment. Similarly, guardianship legislation is rudimentary, and rarely allows partial guardianship, for example. In practice, in much of the Southern African region, the overwhelming sense is of the absence of meaningful legal regulation in the mental health context.

Consistent with this, there appears to be no tradition of engagement of people with mental health problems with the legal system. Legal representation or formal advocacy is not a fixture of the mental health system. Again, this should be placed in perspective: in Lesotho, the state provides defence lawyers to criminally accused persons only in capital cases. It is thus perhaps unsurprising that they are not routinely provided to psychiatric patients.


18 In southern Africa, the Republic of South Africa has particularly good legislation: see Mental Health Care Act, 2002 (RSA Act no 17, 2002) s 32. While not really in southern Africa, other African countries have also passed new legislation in recent years. See Tanzania, Mental Health Act, 2008 (Act no 21/08); Kenya, Mental Health Act c 248 (1991); and Egypt, which passed new legislation (Law for the Care of mental Patients) in 2009.
B. Central Europe

Central Europe raises very different questions. Certainly, these countries are relatively poor by western European standards, but they are considerably wealthier than the African countries discussed above. As table 1 shows, the average annual GDP per head is roughly US$10,000 to 20,000—significantly below western European comparators, but significantly higher than the African examples. Similarly, from a simple demographic point of view, there are a much wider range and stronger concentration of services. Where figures are available, mental health appears to account for something in the range of three to seven per cent of health budgets. Once again, this is an under-fund relative to impact of mental disorders on QuALYs, but these are in general much higher proportions than the African numbers, and are further based on significantly higher health budgets.

This follows through into service provision. In the southern African countries outside the RSA, there are 0.13 to 1.5 mental health beds per 10,000 population; in central Europe, these numbers are generally between 7.5 and 14—notably higher than in the comparitors in developed nations, reflecting in part the ongoing focus on institutional rather than community services in the region. Psychiatrists and other mental health professionals are similarly much more readily available, with up to 15 psychiatrists per 100,000 population. And while organised community care provision is extremely limited in central Europe, there are generally state financial benefits available to people with mental disabilities. While certainly not generous, these benefits do allow a financial cushioning of the transition between institution and community.

Central Europe is thus not a culture where mental health care does not exist. Instead, the issues are about its nature. There may be no shortage of institutions, but the institutions are often sadly inadequate. The reports of the European Committee for the Prevention of Torture (CPT) and other investigative bodies have chronicled serious deficiencies in institutional care in the region. In a 2002 visit to Karlukovo State Psychiatric Hospital in Bulgaria, for example, the CPT found that meat, fresh vegetables and fruit were only rarely available, and the daily per capita allowance for food was less than half a Euro. In practice, the institution relied on donations of food from relatives of the inmates. The CPT noted a connection between the limited food and the mortality rate in the institution.\(^{19}\) While this is certainly a particularly clear example of institutional deprivation, institutions do seem to be generally large and depressing. The common use of ‘cage beds’ and ‘net beds’ in significant parts of the region—beds covered by bars or netting to preclude the occupant from leaving the bed or, often, from standing up—is one indication of the intensity of control and general

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oppressiveness that is still not uncommon. An absence of community-based care means that people may remain in these institutions for long periods of time, particularly if they have chronic disabilities such as learning disabilities.

These are countries that remain influenced by their Soviet past. In a legal context, this means that there are almost always legal structures surrounding confinement, often buttressed with procedural protections. Thus in much of central Europe, civil psychiatric detention may only occur upon the order of a court, for which a lawyer is provided. The problem with these procedural protections is that they are often in form only. The report of the Mental Disability Advocacy Center (MDAC) relating to Hungary provides a particularly clear example of how these rights lack real meaning. Lawyers often meet clients only at the court on the day of the hearing, and hearings last only a few minutes. Indeed, it would seem that in some countries lawyers do not view it as part of their role in these hearings to challenge the confinement, raising the question as to what purpose the hearings are actually meant to achieve. The parallels with the empirical literature on the United States of America 30 years ago are striking.

Once the individual is admitted, plenary guardianship often follows almost as a matter of routine, often with the director of the hospital or social care home being appointed as the guardian. Here, the unreformed nature of the legal systems does create real problems in rights protection. Consistent with classic Roman law, a person under guardianship loses legal personality. He or she ceases to be a legal agent who may enforce his or her rights, and this is regardless of the de facto functional capacity of the individual to make the specific decisions in question.

Southern Africa and central Europe are thus fundamentally different conceptually. Southern Africa is poor, in a world where law is, and has always been, largely absent in the field of mental health. Central Europe is a world still in the shadow of its Soviet past, with large psychiatric facilities, battalions of psychiatric professionals, and a tradition of legal process (although not meaningful legal involvement). These contexts follow through into the questions of service provision, and the question of the place of rights in these regions. For southern Africa, the question is how to build an appropriate system essentially from scratch; in central Europe, the question is how to ‘turn the super-tanker’.

What they share is a history of political and social indifference to mental health issues. In neither region has there been the political support for the development of adequate mental health programmes, nor of the user involvement movement,

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20 Regarding cage beds in particular, see Mental Disability Advocacy Center (MDAC), *Cage Beds: Inhuman or Degrading Treatment in Four EU Accession Countries* (Budapest, MDAC, 2003) available at: www.mdac.info/documents/118_MDAC_Cage_Bed_Report.pdf.

21 The obvious exception is Latvia, which appears to have no functioning mental health legislation.

22 Mental Disability Advocacy Center (MDAC), *Liberty Denied* (Budapest, MDAC, 2004).

23 P Bartlett, T Simmins, M Deric and M Zadro, *An Analysis of the Mental Health Regulations in Bosnia and Herzegovina with Recommendations* (Sarajevo, Council of Europe, 2008).
that has occurred in economically advantaged countries over the last roughly 40 years. In both regions, the question is how to kick-start change.

IV. Rights over the Self

Unless we are to abandon the rule of law completely regarding mental disability in these jurisdictions, the legal starting point must be the assurance of an appropriate legal structure in domestic law. That, along with relevant domestic policy and the financial resources, provides the legal groundwork for the provision of a system of care and support for people with mental disabilities. The specific content of such law and policy is a much wider subject than can be addressed in this chapter. Suffice it to say that, as noted in the first section of this chapter, the legal and cultural traditions are not in place for what people in economically privileged countries would view as appropriate standards of care, and appropriate standards and provision of community-based care in particular.

It is appropriate to remember where the real arguments for this sort of rights lie. Perhaps most significant is the application of power to the individual. Sometimes the authorities are wrong, or at least not so clearly right that they should be allowed to do what they want. Sometimes these errors are manifest—the ambulance attendants bring the wrong person to hospital, for example, or there are clear and material errors in the medical record upon which compulsion is based. One hopes that such egregious errors are uncommon, but experience indicates that they certainly occur. Much more frequently, issues of compulsion will be in a grey area of: how does a legal standard apply to the situation of this individual? This does not alter the fact that the effects on the individual are likely to be substantial—deprivation of liberty, enforced treatment, loss of control over property, for example—and he or she must have a right to ensure that the decision meets the appropriate standards.

The arguments for such rights also concern the governance of those who care for people with mental disabilities, be they professionals or family members. These individuals exercise power. It may be a platitude, but it is nonetheless a valuable platitude that power unchecked is a recipe for power abused. Certainly, the provision of individual rights to challenge these carers is not on its own a sufficient check for such power, but it enforces a particular relationship between the carer and the individual. The experience in economically advantaged countries is that the move towards engagement with users, the rise of the user involvement movement, and the consequent reshaping of mental health policy occurred in parallel with the development of and increased exercise of individual rights of service users. While it is difficult to see that such correlations can be researched with rigour—there are too many confounding variables—it is intuitively arguable that the new, engaged and active role accorded to service users flows, to a relevant degree, from the fact that this active role could be enforced: a
culture has developed in these countries where service users can, in a judicial or quasi-judicial forum, have their voices heard and require carers to justify their actions. Engagement without such enforcement becomes a crumb dropping from the master’s table, at the master’s behest; and in this day and age, that is no way to build a mental health system.

As noted above, these rights often do not currently exist in a meaningful way outside economically advantaged countries. In Latvia and in much of southern Africa, there appears to be no functioning mental health law, let alone a law which creates the opportunity for service users to challenge or engage with the decisions regarding compulsion that are made about them. In much of central Europe, as noted above, persons found incapable under a judicial process, sometimes without notifying them of the hearing, lose their legal personhood, and no longer have standing in court. Furthermore, even in those parts of central Europe where court hearings occur as a matter of routine, they appear often to be mere formalities, with little meaningful engagement with users and their rights.

On some of these points, the situation in central Europe in particular bears some relationship to the American situation in the 1960s: law and institutions exist; the question is how to make the law relevant at the local level. That would suggest that the development of a legal culture for service users might be an appropriate way forward, to take better and meaningful advantage of the existing frameworks. In southern Africa, by comparison, little relevant law exists, let alone a legal culture prepared for litigation in this area. In both cases, we are a long way from a world where it can be taken for granted that users of psychiatric services and people with learning disabilities can in practice contest their rights, and where they will be taken seriously by the legal system.

The difficulties of developing litigation in this area are not merely formal, however. It is not merely that there is no culture of litigation, it is also that the user may well be in an institution where order is maintained by the effect of long-standing institutionalisation, by coercion, or occasionally by violence. Certainly, in a total institution, life for an individual challenging the institution is unlikely to be made pleasant by the institutional staff. It is fair to ask how their safety is to be assured in the roughly six years it now takes between an application to the European Court of Human Rights and its final determination, plus of course the time required for the prerequisite exhaustion of domestic remedies.

Perhaps as problematic is the question of what can rights look like in these cultural contexts? The issues for central Europe and southern Africa appear different here, as central Europe is markedly more culturally similar to western Europe: society within individual countries is not generally based on ethnic or

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24 See, eg Shtukaturov v Russia (App No 44009/05) judgment 27 March 2008. For more detailed discussion of guardianship in central Europe, see the reports of MDAC, available at www.mdac.info.
cultural tribes; court systems, legal systems and psychiatric systems exist in a broadly similar way to the rest of Europe; and there is not generally the grinding poverty of much of southern Africa.

How relevant are the cultural differences between the economically privileged countries in which human rights have developed and southern Africa? Obviously, such differences exist and cannot be ignored, but they must be approached with care, since ‘cultural difference’ can frequently become a mask for stigma and oppression. The African Charter on Human and Peoples’ Rights, for example, specifically protects the role of the family as ‘the natural unit and basis of society’.25 This has led to some debate as to whether families should have a particularly strong role in African mental health law.26 While the role of families in African society, both in practice and in their human rights charter, may be significant, it is not obvious how it should be translated into mental health law. The reality is that mental disability still carries considerable stigma in much of Africa, and the risk is that families will choose not to offer care within the family, but instead to leave an individual in an institutional setting as long as possible. As such, the risk is that this becomes a right to exclude the person from the family rather than to include them.

That said, it is difficult to see that a system of law and rights can work without engagement with local culture. Quite how we should expect that to work in southern Africa is an open question. Certainly, unless patterns of service provision change dramatically, it is difficult to see that the western model of tribunals, with a psychiatrist, a lay person and a lawyer, can function: there are simply not enough psychiatrists. It does not of course follow that rights cannot be pursued. The RSA, which like the rest of southern Africa has a shortage of psychiatrists in some parts of the country, has expanded the psychiatric role on the review board to include other mental health professionals.27 That might provide a different model. Alternatively, in some parts of southern Africa, indigenous courts still exist, and have an active role in the community. One might imagine that they might appropriately be used for determination of matters of dispute. How successful that approach would be no doubt depends on a variety of external factors: Do the courts function effectively and with the respect of all who would be party to disputes about psychiatric coercion? Can they readily be trained with the necessary legal knowledge to apply the statute? And are there issues of stigma among the court officers that would preclude application of a rights-based law in the way the law intends? Whatever is decided, the court or

26 See, eg the article by Dr Ahmed Okasha in the newspaper Al-Masry al-Youm, 4 March 2009.
27 See Mental Health Care Act 2002 (RSA) s 1(xvii), 20(2)(a).
court-like body must have the confidence of service users, mental health professionals, and the local community. We still know very little of how these practicalities will play out in domestic contexts in southern Africa: we are still too near the beginning of the process of legislative development.

For any of this to work, of course, local policy-makers must come to understand the relevance of the issues. It does seem that a critical mass of those charged with care of people with mental disabilities is aware of the problems and the issues of stigma surrounding service users, but it is far from obvious in either central Europe or southern Africa that this constitutes a majority of psychiatric professionals, let alone a national consensus. If we are to see meaningful entrenchment of human rights values in psychiatric and learning disability services in these countries, significant changes of attitude will be required among the bulk of practitioners, policy-makers, governments and the public.

That reminds us that the provision of individual rights is only one part of a much bigger project, involving changed attitudes to users of psychiatric and learning disability services and to the provision of mental health services. If individual rights are merely a part of that larger picture, they are nonetheless an integral part. Appropriate provision of services in the twenty-first century requires safe environments for users, an end to unregulated coercion, an atmosphere of trust between users and service providers, enhanced dignity for service users and a move towards engagement of service users in their care. For these to become more than policy ‘tick boxes’, they must be buttressed by mechanisms of enforcement, and those must include mechanisms for the individual service users to ensure that standards are applied in their cases. Nonetheless, individual rights are clearly part of a bigger picture.

V. Issues of Systemic Litigation and Enforcement

As is well-known in economically privileged countries, individual rights have their limits, and this is nowhere more evident than in the psychiatric and learning disability realms. It has been acknowledged since the ground-breaking paper of Janet Gilboy and John Schmidt over 30 years ago28 that coercion frequently occurs outside law, in situations where ‘voluntary’ patients do not perceive themselves as having real choices in their psychiatric admission or treatment. Further, a significant proportion of users of psychiatric and learning disability services will be in a position of sufficient vulnerability that they will not be able to instigate legal proceedings. This vulnerability may, as noted above, flow from conditions in the individual’s place of care: he or she may not feel that it is safe to ‘rock the boat’. It may also of course flow from the individual’s disability. While

28 J Gilboy and J Schmidt, “‘Voluntary’ Hospitalization of the Mentally Ill’ (1971) 66 Northwestern University Law Review 429. See also Bernadette McSherry, this volume, ch 16.
certainly many people with mental health problems or learning disability are able to stand up for their own rights, the reality is that some are not. Further, and perhaps more significantly, successful litigation of individual rights may provide a remedy to the individual litigant, but may fail to address over-arching and systemic problems in the mental health care system.

Some of the mechanisms to address these problems will not necessarily involve litigation. Boards of inspection, for example, may be an important way to police and enhance standards of care provision, even if they have no right to go to court to enforce their concerns. Their efficacy will however be determined by the appropriateness of appointments made to the boards, and how effective the extra-legal mechanisms are to ensure that their recommendations or findings are acted upon. Even in developed democracies, there are numerous examples of reports and notices of violation issued by these inspection panels left gathering dust, making no meaningful difference. In these circumstances, access to courts by these boards (combined with sufficient budgets to make such access practicable) may be important.

Of greater relevance to the theme of this volume is systemic litigation, either by way of test-case, class action, or other mechanism. The efficacy of this approach in the economically developed world has been patchy. In England, there has been little litigation to enforce standards of service provision, and such litigation as has occurred has by and large been unsuccessful.29 In the United States of America, by comparison, some early cases relating to standards of care and justifications for confinement were instrumental in establishing the human rights culture in a psychiatric context.30 To what degree does systemic litigation represent a way forward for southern Africa and central Europe?

Any optimism must be limited. At best, litigation will only be as strong as the right protected in the formal legal instrument, and key rights in this area are often, to use the prevailing euphemism, ‘aspirational’. As an obvious example, the right to health appears in a wide variety of international legal instruments, but is generally qualified by reference to the ‘best available’ standard of health, or with an express reference to affordability.31 This rather woolly language severely limits the potential success of litigation, providing courts with an invitation to avoid the difficult economic decisions that health care choices involve. Further, many of

29 See, eg R v Gloucestershire County Council, ex parte Barry [1997] 2 All ER 1 (HL); R (on the application of K) v Camden and Islington Health Authority [2001] EWCA 240; R (on the application of Stennett) v Manchester City Council [2002] UKHL 34 is something of an exception, as it requires the state to pay community aftercare services that are mandatory under the Act, although it does not define what services are mandatory under the Act.


31 See, eg ACHPR art 16; International Covenant on Economic, Social and Cultural Rights, UN GA res 2200(A) (XXI), 21 UNGAOR Supp (No 16) at 49, UN Doc A/6316 (1966), 993 UNTS 3 (entered into force 3 January 1976) art 12; European Social Charter (Revised), ETS 163, arts 1(11), 11.
these rights are contained in international instruments that have no enforcement mechanisms for individuals, and may not be incorporated into domestic law.

Nonetheless, there are some indications that systemic litigation may sometimes be a useful way forward. In Bulgaria, for example, recent cases brought jointly by the Mental Disability Advocacy Center (MDAC) and the Bulgarian Helsinki Committee have resulted in findings that Bulgaria’s failure properly to educate children with intellectual disabilities constituted a violation of the European Social Charter, and that differential payments to people receiving community benefits based respectively on age, learning disability, and mental health problems was discriminatory under Bulgarian domestic law. In Russia, an MDAC test-case relating to procedures of guardianship has resulted in findings both at the European Court of Human Rights and the Russian Constitutional Court that the procedures for assessing incapacity and awarding guardianship must be fundamentally altered, to allow significant involvement of the person allegedly lacking capacity. In the event that these cases result in significant systemic reforms, real and tangible results may follow for large numbers of people. At the international level, European Court of Human Rights jurisprudence has established broad framework requirements for civil detention, although it has been less helpful in establishing minimal standards of care in facilities.

A caveat is appropriate, however, in that the existing structures of human rights import an agenda as to what sorts of right are important. There is little doubt that it is easier under the European Convention on Human Rights for example, to ensure standards of care in facilities than it is to require the provision of care services in the community. The result of litigation in this area, therefore, might well be that funds are spent to improve facilities, at least to the point that they are no longer violating human rights. This presents advocates with a dilemma. If expenditure is made in this way, people will still be in the institutions; merely in marginally less bad institutions (or, conceivably, good institutions?). It is difficult to see that governments that are required to spend money on these institutions will quickly abandon them for community models of care: the focus on institutional models of care is thus buttressed, not challenged. At the same time, is it really acceptable not to litigate the standards of care in these places, and thus to leave people in manifestly sub-standard conditions, in the hope that community services may come?

It is not obvious that the human rights priorities necessarily match the priorities of the service users. To take a concrete example, I have in central

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32 Mental Disability Advocacy Center (MDAC) v Bulgaria, European Committee of Social Rights, complaint 41/2007, decision of 10 June 2008.
33 See Shitukaturev v Russia (App No 44009/05) judgment 27 March 2008; see also decision of Russian Constitutional Court, 27 February 2009.
34 See Winterwerp v The Netherlands (1979) 2 EHRR 387.
35 See, eg Herczegfalvy v Austria (1992) 15 EHRR 437, where prolonged handcuffing of an individual did not violate the prohibition of inhuman or degrading treatment.
Europe visited a ward where everyone was dressed only in nappies. There was no obvious reason for this—the residents did not appear to be incontinent. Unsurprisingly, I found this situation distressing, and I suspect if the situation found its way to litigation, there would be a good chance that a court would make a finding of degrading treatment. It is much less obvious that the people on the ward viewed the situation as intolerable. The visit did not allow me to speak with the residents, but it is further fair to wonder whether the matters that were of concern to them are matters that human rights law would rate as important.

VI. Conclusion

In the background of much of this discussion has been the discursive power of rights. In the period after the fall of the Berlin Wall, there was tremendous enthusiasm in central Europe for engagement with the western European conceptions of rights, in part as a way of drawing a line under the events of the previous half century. While the subsequent 20 years have taken some of the bloom off the rose in this regard, rights continue to have discursive power in these countries.

Africa, once again, is different: with the exception of the RSA, human rights do not appear to be articulated as the marker for distinction from an old and oppressive régime. Instead, the risk is that human rights are perceived as merely the latest form of colonialism, creating a much more ambiguous climate for reform. That said, African nations are signing up to the key United Nations human rights instruments, and Africa does have its own charter of human rights, buttressed by its own African Court of Human and Peoples' Rights.

Insofar as the discursive power of rights and law can be harnessed to the advantage of people with mental disabilities, it may well be a helpful tool in bringing about systemic reform to mental health services. It allows service users to be re-created as persons with a role and a stake in the care system—a development largely taken for granted in economically privileged countries, but which is still largely absent in central Europe and southern Africa.

So where does this leave us? Rights do matter. They matter because sometimes they matter in individual cases; they matter because sometimes the political culture of rights and also their discursive impact can influence governments into useful action. Certainly, both those objectives are important. We have also known, since the earliest days of the law and society movement, that rights only


matter if accompanied by political and social advocacy, before, in parallel with, and after litigation. There can be little doubt that this is a lesson that must also be applied in central Europe and southern Africa. Rights do not happen in a vacuum. They happen as part of social and political movements. They are, however, a necessary part of those movements.