INTRODUCTION AND WELCOME

The Dean of the Faculty of Law, Ron Daniels, welcomed the participants to the workshop. His presence reflects the Faculty's strong interest in health law and policy and in linking the academy with policy makers. He noted that, as lawyers, we like to believe that what happens in the nation's courtrooms is fundamental to shaping public policy; somehow, every public policy issue ends up being framed as a matter of law that can be brought before the courts. Whether or not that is a good thing is the focus of today's discussion. Dean Daniels concluded by thanking everyone for participating in the workshop.

SESSION ONE: THE CHARTER AND HEALTH CARE

Reflections on Auton and Chaoulli:
Professor Martha Jackman, Faculty of Law, University of Ottawa

Professor Jackman's presentation aimed – in light of the Auton and Chaoulli cases – to consider the issue of what Charter related health challenges are 'on' or 'off' the table; and what is required to “Charter-proof” the health care system.

With respect to Auton, clearly there was some conflict between the lower courts and the Supreme Court with respect to the significance of factual evidence and the analytical framework provided by section 15 of the Charter. It is argued that Auton is bad law in

---

1 Section 15 of the Canadian Charter of Rights and Freedoms (the "Charter") says:

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without
terms of substantive equality principles and its impact on the health care system. Chief Justice McLachlin’s narrow analysis of the issue predetermined the answer. By focusing on benefits claimed under law, McLachlin CJ focused on core medical services provided by the provinces and non-core services which are only partially funded. In making this distinction, the Chief Justice could conclude that the therapy the plaintiffs were seeking was not a benefit conferred by law. She distinguished *Eldridge* by saying that was really a case of under-inclusion, whereas *Auton* was a case where the benefit simply was not conferred by law. The Canada Health Act (“CHA”) and the provincial insurance plans were not designed to provide care for all conditions but only those services provided by physicians and services provided in hospitals. McLachlin CJ found that the appropriate comparator was not Canadians generally but other people receiving non-core therapies and thus she concluded that, on the evidence in the case, there was no differential treatment. The families had put forward no evidence as to how the BC government responded to other requests for novel therapies and in the absence of this evidence one could not find discriminatory treatment. Treatment could legitimately be denied or delayed because of factors such as the uncertain nature of the treatment and its high costs – this weighs section 1 type considerations in a section 15 analysis. It was also suggested that the evidentiary record was insufficient to address the section 7 claim. In particular, McLachlin CJ found that there was not enough of a record to address the issue of whether there had been deprivation of the plaintiffs’ section 7 rights.

________________________________________________________

(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

2 Section 1 of the Charter says:

1. The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

3 Section 7 of the Charter says:

7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.
In terms of Chaoulli, it was noted that we are still waiting for the Supreme Court to rule. In that case, the challenge was to provisions of the Quebec legislation that prohibits private insurance for publicly funded services and prohibits private funding for hospital delivered services. The Quebec legislation does not per se prohibit private care but the appellants/interveners argued as if there was also a per se prohibition on private care of the type Ontario has since enacted. There was conflicting evidence at trial around the impact of introducing a “multi-payer system” in Canada. The trial judge accepted evidence that there were significant delays in the current system but accepted the government’s evidence that introducing multiple payers would be disastrous for the public system. The trial judge found a right to health care under s. 7 and that it is threatened by possible future delays to getting care. However, she determined that the Quebec legislative prohibitions were in accordance with principles of fundamental justice because they balance private interests in access to care with the collective interest in access to care. The Quebec Court of Appeal, in essence, concluded that the appellants’ claim involved commercial rights that are not protected by s. 7. In the Supreme Court, the Quebec government argued that s. 7 does not engage health care interests and thus the claim is non-justiciable. The Canadian Medical Association (CMA) and private clinics from British Columbia argued that the government had to ensure either no delays at all for care, or open up the system to private care. The Kirby Senate Committee argued that the government needed to introduce health care guarantees to ensure timely delivery (but not arguing for a specific right to publicly funded health care). In a factum submitted on behalf of The Charter Committee on Poverty Issues and the Canadian Health Coalition, Professor Jackman had argued that s. 7 gives a right to publicly-funded health care.

In the light of these two cases, what can we say in terms of Charter-related health care challenges are now on or off the table? Professor Jackman argued that what remains on the table are universality claims within the meaning of the CHA – i.e., claims against discriminatory treatment or unequal access to core medical services or non-core services that are already being funded. An example of this would be a claim concerning the disparity in access by Aboriginal Canadians to health care services. Auton leaves such
challenges on the table. Also on the table are claims concerning discrimination in access to abortion services. Cases before the Manitoba Trial Court in 2004 (Jane Doe I and II) have found that, based on Morgentaler, Manitoba’s failure to provide full funding for abortion services, including in non-hospital settings, was a violation of ss. 7 and 15 of the Charter. This fits within the Supreme Court’s analysis in Auton. The more difficult claim that still remains on the table is whether s.15 may be violated with respect to non-core services where there is evidence of discriminatory treatment with respect to novel or emergent therapies.

Off the table are comprehensiveness claims, i.e., s. 15 claims for non-core services where funding is denied or delayed because of uncertainties regarding treatment, delays or difficulties in funding.

Professor Jackman argued that the distinction that Auton draws between universality and comprehensiveness is bad law and inconsistent with the Court’s reasoning in Eldridge. If Auton is to some degree fact-driven, there is a range of health related Charter cases that are in the grey zone including the failure to provide certain mental health services. Also, under-funding and the failure to ensure long-term health care services are gender discriminatory actions. Lack of funding for pharmacare is discriminatory with respect to age and poverty. Lack of addiction treatment is discriminatory in terms of racism, disability and addiction. If Auton was dictated by its facts those types of claims might well still be worth pursuing.

With respect to Chaoulli, we do not know what is off the table yet. What is on the table is the issue of whether a ‘right’ to private care is protected by s. 7 of the Charter, whether waiting times are a violation of s. 7, and whether s. 7 gives a right to provide “core” health care services outside the public system.

Charter litigation is not necessarily a cure for what ails the health care system. Core health care needs for groups whose needs are not adequately being met need to be addressed, such as failure to meet needs of Aboriginal people, addiction services, and
reproductive health. It is not clear whether waiting times are a threat to health in Canada, but there is a public perception that they are unacceptable. Evidence of government attempts to manage waiting times is required along with evidence that there is an on-going balancing of competing needs when waiting times are a problem. There is an issue of fairness in decision-making processes with respect to unreasonable waiting times.

Further examination is needed of decision-making processes around what is ‘in’ and what is ‘out’ of the Medicare basket. Who is involved in decision-making, and on what basis are decisions being made? At present, the system cannot demonstrate that these decisions are made in a rational and systematic way. In terms of who is involved, there are many concerns about who has authority and who is excluded. In terms of the basis on which decisions are made, there has been much debate about evidence-based decision-making (EBDM) in policy decision-making. Finally, the experience in Eldridge highlighted the heavy burden that governments have to bear at the s. 1 level when defending Charter cases that the courts find attractive. Is this a false economy? Is the government spending more than it is saving through its refusal to fund services? Governments are not able to answer that question; they do not have the evidence at hand or have not been effective in communicating that evidence to the Court. Their ability to justify decisions under s. 1 is constrained by their inability to show evidence about their decision-making processes.

Charter values underlie the publicly funded health care system and s. 15 values underlie most of the systemic health reform recommendations currently on the table. Charter review provides a positive opportunity to assess decisions and provides a positive framework for assessing conformity of the system with the values on which it is based – i.e., equality/fairness/individual vs. collective interests. To do this properly places a heavy onus on Charter mobilizers, their legal counsel, on governments defending these claims, and also on the judiciary, which is clearly not trained for, or too fond of, this kind of task.
Legal Mobilization and Health Care Policy:  
Professor Chris Manfredi, Department of Political and Canadian Studies,  
McGill University

Professor Manfredi focused on the *Auton* case and referred to the “reversal of fortune” – after winning several victories in the lower courts, the plaintiffs suffered a reversal in the Supreme Court where the claim was denied. *Auton* and *Chaoulli* are of great interest when put in context of legal mobilization, which is “the use of courts to effect policy change”. Two of the things that Professor Manfredi is looking at in a current project are what does this type of litigation mean for a) groups that litigate; and b) public policy decisions. *Chaoulli* and *Auton* are the most recent and visible manifestations of what have become a common phenomenon: the use of rights-based litigation to effect health policy reform. Apart from *Morgentaler*, which established a new abortion scheme, previous cases have operated at the periphery of the health policy field. However, *Auton* and *Chaoulli* are different. *Chaoulli* challenges the very foundation of Canada’s health care system and *Auton* challenges provincial autonomy over health care plans. This discussion will focus on what the cases say to the phenomenon of legal mobilization. As a strategy for policy reform, legal mobilization aims at establishing a new legal rule that will generate desirable policy consequences. However, the reality is more complicated. It can fail to establish the legal rule change sought but desirable policy consequences may nevertheless follow; or, the rule change may result but no desirable policy consequences might follow.

There are three key questions about legal mobilization: (i) how do cases get into the legal system; (ii) under what conditions are such claims likely to be successful; and (iii) what is the impact of winning or losing for the broader policy environment?

There is a debate in the political science literature about whether or not legal mobilization is effective. In the early 1990s, Rosenberg⁴ wrote a book called “The Hollow Hope” where

---

he argued that legal mobilization is not an effective instrument for social reform/policy change. Rosenberg said there were systematic, institutional factors about the legal system that make litigation ineffective (such as limitations on constitutional rights and limited judicial independence). He did suggest there were some conditions under which litigation might be a good thing including incentives for key actors to change, costs of resisting change, and effectiveness where court orders could be leveraged to extract additional resources. One downside is that litigation can energize a counter movement and have negative results as a consequence. McCann argued that Rosenberg failed by looking too narrowly at positivistic outcomes and that Rosenberg ignored the constitutive aspect of law. Legal mobilization can help to push forward the cause of disadvantaged groups, and even legal losses might have positive consequences.

_Auton_ is the only case in Canada for which we have a completed story. The case entered the legal process with a single objective – to obtain a remedial order of _mandamus_ to fund a particular treatment for autism as a necessary service in the public health care system. In the lower court, the plaintiffs never got that outcome (i.e., a declaration that the treatment is the only medically necessary form of autism treatment). However, they achieved judicial orders saying that British Columbia (BC) had to fund in general a generic type of intervention for autism. The families were also awarded monetary damages; they got a judicial order granting funding for treatment the children had been receiving. In general, in the lower courts the plaintiffs won at every level. When the case reached the Supreme Court, the outcome was dramatically different. It was a stunning legal defeat.

The Supreme Court reversed the lower court decisions and held that BC’s refusal to fund the treatment did not constitute discrimination under s. 15. The Supreme Court said the issue before the court was not what the public health care system should provide but whether failure to fund could be a violation of the Charter. The Court drew a distinction between decisions about what should be included in the health care basket and decisions

---

about services that were already provided. Four factors drove the judgment; the first two factors provided a benign picture of the situation, while the second two were legal factors. The four factors were: 1) the controversial or emergent nature of the autism treatment under consideration; 2) the existence of some government funded programmes for autistic children and their families; 3) the court’s finding that the claim did not involve a benefit provided by law and, even if it did, there was no discrimination in the decision not to fund it; and 4) if this was a benefit, could there be a claim for discrimination? McLachlin rejected the suggestion that autistic children could be compared to non-autistic children, but said that to succeed on the discrimination claim you would have to find someone who is non-disabled and receiving a benefit not defined as a core medical service. It was a complete rejection of the legal aspect of claim.

The Supreme Court found that there were no constitutional deficiencies in the government’s decision-making process.

The emergence of a rights-based argument for funding for autism treatment in Auton was no accident; there was a network dedicated to getting access to treatment by legal action. However, Families for Early Autism Treatment (FEAT) in BC raised the stakes by framing the issue as a Charter claim. Why did they succeed? A number of factors: they had sympathetic plaintiffs; good facts (family sacrifice and individual progress under treatment); and a favourable venue in the BC courts. This begs the question why they were not successful in the Supreme Court? Professor Manfredi suggests that it was because the Supreme Court chose an alternative factual framing. It emphasized the controversial, emergent aspect of the treatment, and the BC government’s efforts to provide behavioural therapy to autistic children. Secondly, the Supreme Court took a different understanding of Eldridge, saying it did not assist because it concerned a benefit

---

6 The Court said the benefit is one to core medical services as defined by the province and if the service is not defined then it is not a benefit and cannot be denied. The government is free to target social programmes as it wishes so long as it does not do so in a discriminatory manner.
already provided. Third, although not cited in case, is the court’s decision in *Gosselin* in which it held that a differential welfare scheme for young adults did not violate Charter rights. That judgment is easily transferable to other social programmes; it says that the range of options open to government should not be unduly narrow.

*Auton* offers an important glimpse into the benefits and limitations of legal mobilization. Legal mobilization can fail to establish a desired legal rule, but even when the case was legally successful (in the lower courts) it provided FEAT BC with mixed results. It also led the BC government to convert a pilot programme of autism treatment into a fully fledged government policy. As well, it supported movements in other provinces. On the negative side, even when legally victorious, FEAT BC never got that legal declaration it sought that the treatment was the only effective treatment for autism. The courts were reluctant to make such a declaration which they saw as outside their area of expertise. The decision mobilized public opinion: an Ipsos-Reid poll reported that 84% of Canadians supported public funding despite the Supreme Court decision.

The *Auton* story is consistent in some ways with both sides of the legal mobilization debate. It nudged public policy in the desired direction, energized the movement, and raised public visibility. It did not generate a counter-movement like in the abortion cases.

Both *Chaoulli* and *Auton* seem to be products of Canadians’ frustration with the inability of health care decision-makers to provide the desired level of service. However, the benefits and costs of using legal mobilization require close attention. When litigation is successful, the courts may be able to direct governments to move quickly. But the downside means that the articulation of policy demands in the form of constitutional rights can exclude other policy alternatives; the adversarial nature of litigation is not necessarily best suited to resolving complex policy issues; and, rights based litigation by definition imposes national solutions on regional programmes which ignores differences between provinces. It is important to keep these things in mind. It is necessary to

---

*Gosselin v. Québec (Attorney General) [2002] 4 S.C.R. 429*
examine the implications of this kind of legal mobilization for the health care system as a whole and whether it is a good route to follow.

**Panel Discussion:**
**Professor Bernard Dickens (Chair), Professor Antonia Maioni, Professor Bruce Ryder, and Ms. Nola Ries.**

Professor Dickens called on each panelist to make a brief statement in response to the presentations.

*Antonia Maioni:* The topic being discussed is how the courts are introducing a new dynamic into health care policy making. Why are they doing this and what are the impacts of the courts’ involvement? What came out in both presentations was that while we talk about the courts as a new actor, we are also talking about the multitude of other actors in terms of litigants who are mobilizing to use the courts. There are many reasons why individuals and groups would choose to do so. The sense that Professor Maioni gets is one of frustration; a sense that the courts provide advantages compared to the other avenues in the political process for voices to be heard. The courts are more open for individuals to be heard, and the formal threshold required for entry into the process is minimal compared to the political process. There is also a sense that the courts are advantageous because they are impartial and they lend a moral legitimacy to claims that is not necessarily the case in the more traditional legislative environment. As well, decisions of courts carry more weight in complex disputes. One of the advantages of using the courts is the forcefulness of results: remedies can be specific and can be backed by sanctions. Professors Maioni and Manfredi would argue that there are also disadvantages: first, there is narrowness in using litigation in complex political disputes where policy demands articulated as Charter rights can exclude alternative policy choices from

consideration. Second, courts are normally best suited to resolving disputes between two parties and imposing restrictive remedies on those parties. However, in health care there are many stakeholders and the facts and evidence changes constantly. Thus, the adversarial nature of litigation is not well suited. Third, there is a question of national scope. We are talking about health care with the erroneous assumption that it is an area upon which the Supreme Court should be making decisions. We are trying to impose national solutions on what historically/politically have been decisions driven by local concerns. National solutions may ignore differences among provinces, and may not give enough weight to the way in which provinces try to find innovative solutions to policy problems. Professor Maioni suggests looking at decisions in the European Court of Justice, with respect to how a supranational body can interfere in national decision-making bodies.

Bruce Ryder: Professor Ryder stated that he found Professor Manfredi’s comments with respect to the problems of litigation very helpful. There is real truth to each of the concerns expressed about legal mobilization. They are concerns of which the courts are acutely aware, and much of the recent decision-making demonstrates real hesitation about getting deeply involved in this type of litigation because of these concerns. It shows up in a number of levels: in the narrow interpretation of rights; in deference to governments (especially where there are large redistributive consequences); and also at the remedial stage of Charter analysis. The courts are more sophisticated in achieving a balance between imposing a normative framework flowing from rights and freedoms; and the primary law and policy-making decision responsibilities of government. They can craft remedies so they are not telling governments what to do – e.g., declare status quo to be unacceptable but simply charge government with consulting broadly and coming up with a solution. Sometimes all courts do is to say that rights have been violated, but they do not tell governments what to do about it; they just say that something should be done. We need to think about the courts’ remedial authority and how they go about exercising it. We need also to consider human rights legislation across various jurisdictions, as some discrimination cases are going to human rights tribunals rather than to the courts. There
is a real reluctance to interpret s. 15 broadly and generously and the hurdles are burdensome to claimants, whereas burdens under human rights discrimination law are much easier for claimants. There is a growing disparity between a constitutional understanding of equality, and of human rights law. Courts seem to be afraid of s.15 where it involves them in policy too much. Some of the cases that are “off the table” after *Auton* may turn up in human rights tribunals.

*Nola Ries:* Ms Ries noted the downsides of some of the rights claims. Where governments are making policy decisions, they need to have reasonable room to manoeuvre and some of these rights claims can cut down that room. The courts are not always in the best position to take on that task. There is a need for more transparent and robust systems for policy-making. Another downside of this situation is the fact that even if a claim is successful, this does not mean the outcome will favour the litigants. Even if a government is told that they are violating rights, they can always turn around and fix it the way they choose and there might be an overall reduction in benefit levels. There was some criticism post-*Eldridge* that, even though the court said the government had an obligation to fund interpreters, implementation of that change took a long time to happen. So even if claimants succeed in their claim, the implementation may be lacking or delayed. With respect to ‘Charter-proofing’, Ms. Ries wonders if governments might shy away from funding non-core services, because if they do not fund them at all then they can say there is no claim to be made at all, as per *Auton*.

**Audience Discussion**

(NB: Audience members who participated in the discussion will not be identified).

*Maioni:* When the courts become an actor in health care, it’s a way of mobilizing public opinion. With *Chaoulli*, the matter went from being championed by a lone crusader to becoming a real lightning rod in terms of public debate about the whole legality of the ban on private insurance. The idea of having mobilized public opinion came out because justices pushed hard on the whole idea of whether this was an isolated case or something
deeper in the system and this speaks to the idea of how these cases mobilize and divide public opinion. Could Professor Jackman speak to the mood of the court?

Professor Jackman responded that, by the time the Chaoulli case reached the Supreme Court, it was not about the claimants any more; it was a debate between the interveners that supported two-tier health care and those that did not. There were some very highly paid, very effective lawyers. It was a battle between private and public health care and the case became a platform for it. For the justices, it was also public vs. private health care and it did not have a lot to do with the facts any more.

Ryder: Why didn’t the court care about the fact that the patient was waiting for surgery in Chaoulli?

Professor Jackman noted that the evidence was not great for the patient. He insisted on consulting multiple specialists and there was no imminent threat to him. The s. 7 harm was the potential future threat and that was a weak link in his argument.

Audience: Why was Chaoulli heard in the Supreme Court, especially if it was not a strong case for the plaintiff? Why did the Supreme Court select this case to be heard?

Professor Manfredi responded that we do not know very much about the factors that Courts take into account in granting leave to appeal. One interpretation might be to nip these kinds of cases in the bud. Another might be a more strategic political interpretation – perhaps the court wants to be a player in political/policy issues and this is a huge issue. Professor Manfredi views the Supreme Court as a political institution which needs to assert its role as an actor in the policy process while avoiding counter movements from other actors.

Professor Jackman noted that some members of the court are very ideologically supportive of the claim. She also noted that granting leave to appeal does not require the whole court, just a panel of three judges.
Professor Ryder stated that he is not sure that the court is so keen to get involved in political debates, but suggested that they know they are going to get a case like this eventually so they might as well deal with it sooner rather than later.

*Audience:* What exactly is the frustration discussed?

Professor Jackman responded that in *Chaoulli* there was frustration among elites that they were not winning, that public opinion still supports single-tier health care.

Professor Maioni suggested that the frustration reflects concerns that Canadians have about whether they will get access to care when they need it. The frustration is the idea that people are concerned about the capacity of the health care system to address their future needs (i.e., questions about the capacity and sustainability of the system).

*Marchildon:* Would it be useful for litigants in future cases to think about there being two baskets rather than one basket? The first is the traditional basket with a national dimension as per the CHA; while the second basket does not have a national dimension but is defined purely by provinces and territories. When the court comes forward with a national remedy, it will thus only apply to those services with a national dimension and would respect the division between the broad national dimensions and the provincial aspects.

Professor Jackman responded that her impulse as an anti-poverty activist is to move everything into the CHA basket because of the condition around accessibility. *Auton* has put a big hole in her work in this regard. She is not attracted to the idea of regional and provincial variations, but wants everything to be national. Professor Marchildon responded that moving everything into the CHA basket automatically imposes universality and prevents user-fees of any type, which would come at a very high price for the provinces. Professor Jackman commented that the problem with *Auton* is that the distinction between welfare programmes and health is inherently discriminatory.
Professor Maioni said that she is struck by the observation with respect to CHA services vs. non-CHA services. She has never heard this characterization in Quebec. She questioned whether there is confusion about medically required vs. medically necessary? What do these different terms mean?

Professor Manfredi responded that the trial court judge in Auton misunderstood the testimony of Morris Barer from the Canadian Institutes for Health Research (CIHR). Barer was asked ‘what is a medically required service’ and he said that it is something that cures or ameliorates illness. Professor Manfredi suggested that one of the ironies is that although McLachlin CJ talked about leaving room for provinces to act, the decision may have a chilling effect – i.e., why would a government add something new to their basket when doing so may open themselves up to a constitutional challenge (as Ms. Ries had said).

Professor Jackman discussed the distinction between the principles of universality and comprehensiveness and noted that they tend to be conflated. She noted that universality refers to equality, while comprehensiveness refers to the idea that everyone’s health care needs should be met at the end of the day, and this is open to an equality analysis. Universality is defined in a circular way, what the province decides one person should get, everyone should get. Auton reflects the idea that the Charter only begins to apply when the provinces have decided what is in, but Professor Jackman argues that this reasoning is perverse.

Ms. Ries questioned what impact having different baskets would have on the primary care trend to emphasize multidisciplinary care. She suggested that having different baskets would work against this trend.

Audience: With reference to this chilling effect, as we modernize and introduce new services, there will be services that we will want to take out. Does the Panel think that Auton will have an impact on delisting, changing and modernizing the system?
Professor Manfredi responded that the Supreme Court in *Auton* left open the question of whether taking something out of the basket is justiciable. So this still seems to be left on the table.

Professor Maioni noted that it is politically difficult to take things out of the basket.

*Professor Dickens: Is this where the contrast between core and non-core services matters? Would there be relative freedom to de-list non-core services?*

Professor Jackman responded that the likelihood of a successful challenge to non-core services being de-listed is very low. The *Auton* decision provides some good markers for what would be good decision making: i.e., it focuses on evidence of effectiveness, balancing costs of treatment within the system, etc. The Charter provides good indices for good decision making that is fair and does not discriminate but the trouble is the institutional ability of governments to reorganize the system given competing interest groups involved – a chill is easier than a fix.

*Audience: With reference to the impact of *Auton*, and the extent to which *Auton* moves away from *Eldridge*, we have to raise the question as to whether *Eldridge* is really a case about health care. *Eldridge* was more about accessibility to a government service per se, rather than focusing on the service itself being health care. Whether the service had been education or another government provided service, the question at issue in *Eldridge* was whether the service was accessible to all groups? Was the court’s problem in *Auton* that they were seeing it as quite a different case?*

Professor Jackman responded that if *Eldridge* had been framed as a claim to health care pursuant to s. 7 of the Charter, the plaintiff probably would have lost. However, it was viewed as an equality claim. She suggested that money is a key factor in these decisions; there is an idea that health care claims cost a lot whereas it is not necessarily the case with equality claims.

*Dickens questioned whether autism could be dealt with as an educational issue.*
Professor Jackman responded that in Ontario at the trial court level, the courts have been willing to ignore *Auton* and say this is education and this is a right. From a disability rights perspective, the suggestion was not that children with autism should be medically treated and cured but offered services that are appropriate to them and that they should be accommodated – this is a very different analysis.

*Audience:* A participant raised an issue regarding core vs. non-core services and *Auton*. The question was how ‘medically necessary’ services are defined and whether the fact that in a hospital, care is provided by a team, not just doctors and is this discriminatory to people who need care from those kinds of providers but are not in hospital?

With respect to the difference between ‘medically necessary’ and ‘medically required’, it was noted by one audience member that, historically, the term ‘required’ was used because it would be up to the physician to decide, but it was questioned what this means now. Professor Maioni questioned whether we are going to allow the courts to decide this? Or are we going to change the CHA to make it more specific? Another audience member suggested that, in a federal system, it is unlikely that the federal government will ever take that step. When the CHA was enacted the federal government charged the provinces with determining the definition of medically necessary and medically required in consultation with the provincial medical associations, and the federal government wants it to stay this way.

Professor Jackman suggested that it is impossible to come up with a good definition. What is needed is good decision-making processes that meet the requirements of ss. 7 and 15 requirements. Professor Maioni also noted that besides the issue of proper decision-making processes, it is difficult for the federal court to weigh in because of jurisdictional issues.

*Audience:* One must consider the issue of drugs for rare diseases, or orphan diseases where there is little evidence of effectiveness of the drugs for treatment. It was noted that the provinces get caught with trying to make decisions (about drug coverage) on sound
evidence, and that globalization (use of similar drugs in other countries) has a big impact on how provinces make decisions. But this process is not managed very well; determining how to integrate 14 health care systems is very complex.

Professor Dickens responded that if the federal government identified core services that were necessary then they would have to fund them; so perhaps the federal government does not want to commit themselves to providing core services throughout the country. He questioned whether there is there any way forward on this. Could the provinces and territories define for internal purposes what are core services? Is it a question of one large basket and 14 smaller baskets?

Maioni: What would have been the impact if the Supreme Court in Auton had it upheld the lower court decisions?

Professor Jackman responded that there would have been a declaration that a failure to do anything for the patients was violation of the Charter and the BC government would have responded that it is already doing something.

Lunch: Keynote Lunch Speech by Professor Greg Marchildon

Professor Marchildon’s talk focused on the provinces because they have the constitutional responsibility for the administration of Medicare. In addition to that, they also administer numerous programmes outside of the so-called “core” of Medicare. If you are going to talk about governmental response you need to understand the provinces. First, Professor Marchildon made an observation with regards to the Romanow Commission. At that time, Commissioner Romanow wanted to keep the Commission within the traditional bounds of parliamentary democracy/sovereignty – with less emphasis on the Charter of Rights and Freedoms and the Courts – even though he did want an unprecedented citizen/provider input. Professor Marchildon referred to Western Canada’s perspective on the role of the courts and noted that Saskatchewan was the province that worked through the courts to
create Medicare. This wasn’t very different from what the Hall Commission did years before. Emmett Hall was personally responsible for the so-called Health Charter. It was meant to be non-judiciable; a set of expectations and responsibilities. This is in a very different category to what has been discussed this morning. It is very different from the Senate Report’s so-called “health care guarantee”. For the provinces, the recent and future court decisions are ultimately about their democratic responsibility for allocation of resources under their provincial health care systems.

With respect to the discussion about two baskets, Professor Marchildon noted that one set of services are provided in a certain way because of the CHA, but the provinces set out in greater specificity what the basket contains as a whole. The CHA says that provinces must provide them in a certain way – they must be publicly administered, there must be no user fees, services must be accessible, etc. Once you get out of that category of services, there is another category which is provided in many ways – it is multi-payer, it is not universal, and user fees abound. There is a huge variability across the country, whereas for CHA services the variability is at the border, everyone understands what the core is.

At the root of the problem is decision-making with respect to allocation of resources. Canada has a highly decentralized system of health administration and delivery relative to other OECD countries. Moreover, physicians have a lot of autonomy in deciding what is and what is not medically required.

Professor Marchildon then discussed how he would answer two simple questions:

1) Has recent litigation made provincial governments nervous?; and
2) If so, what are governments doing in response?

He noted that logic is required for him to answer these questions as he has been out of government now for a while. It would seem, however, that most provinces are nervous about these decisions and their potential impact. This is evident with respect to Auton because the majority of provinces have intervened in that case. The only surprise is that, given the importance of both of these cases, not all of the provinces and territories intervened. It is natural that they would be very concerned. If the Supreme Court had
not made the decision it did in *Auton* then, in terms of provincial budget allocations, the precedent would have been set for the delivery of services by virtue of the interpretation of the Charter. Budget allocations in the short term are a zero sum game. It would have created a precedent for future cases that significant allocations would be decided by the courts.

With respect to the second question, the question is more properly ‘what can the provinces do?’ They can reallocate to high risk areas, ensuring rapid diagnosis. But that is already happening; there is much investment in this regard. There is rapid movement which has little to do with the September 2004 F/P/T agreement\(^{10}\) but with pressure brought to bear by the public, and pressure to respond to patient dissatisfaction. We are seeing a shift, but is it a shift for the better? You can Charter-proof legislation but how do you go about doing that? In every province and territory you have individual hospital legislation. How do you Charter-proof that kind of legislation? And if you could, the public response would probably be pretty negative. But the little stones in the basket, the year-by-year decisions as to what is added in, this is not Charter-proofing but is instead not permitting it to become a benefit.

Or, provinces could be very quiet about their decisions – do it on a case-by-case basis, not saying that something is a benefit but making sure those who are vocal about their needs, get what they want so they stay quiet. Professor Marchildon suggested that this would not a good way to go about it. If there was actually a review by departments of justice of their hospitalization legislation, the reaction would be reactive. Change is more likely in the provinces after a major Supreme Court decision that upsets the *status quo*. There is an impact through labour mobilization because governments are responsive to pressures; it creates a dynamic which can result in change.

Professor Marchildon provided the following example. Prescription drugs are not covered under the CHA. There is a type of drug with some controversy (beta interferon) to deal with relapsing Multiple Sclerosis (MS). Saskatchewan has a drug formulary Committee that makes decisions about which new drugs will be put onto the formulary. It is a very dynamic and changing area. The Committee makes its decision based on clinical effectiveness, and sometimes cost effectiveness in a relative sense (compared to other drugs). The Committee decided that the drug in question should not be put on the formulary. Initially, no-one in the Cabinet knew about the Formulary Committee’s decision, but very soon there was a lobby by a patient group that was very effective. The issue came back into the Cabinet room every week. It came in through “state of the nation”, a period of open time when ministers can talk about anything. Individual cabinet ministers were being lobbied about the drug and so raised the issue during this time.

Finally, the item was brought in formally, the health department made its arguments that the Committee had made the right decision, that the drug was not cost effective, and should not be on the formulary. The individual presenting the item did not have his heart in it and other members agreed with technical reasoning but not with impact of policy. Professor Marchildon – Cabinet Secretary at the time – received a call from a senior executive at the drug company shortly thereafter; he offered to subsidize the cost if the drug was put on the formulary. There would be no cost to the government for the first year. The lobby was funded in part by the interested drug company. After about eight discussions, the cabinet decided to overturn the Committee’s decision. This created a ricochet effect. Other provinces without the drug on their list were put under pressure to include the same drug. Professor Marchildon argued that this is not a good way to make public policy. It would have been interesting if the case had been taken before the courts, which is what happened in the UK. There, the Court found that the health authority in question had to fund this drug. The NHS had decentralized and part of the reasoning of the Court was that the NHS policy recommendation was not mandatory because of the decentralization; it was up to the local authority to make an independent decision.
Professor Marchildon noted that there are arguments by some that decisions need greater transparency/input. He questioned how a province can ensure a greater direct democratic input into resource allocation decision-making.

SESSION TWO: RIGHTS TO HEALTH – AN INTERNATIONAL PERSPECTIVE

Rights to Health in South Africa:
Lisa Forman, Faculty of Law, University of Toronto

At the outset, Ms Forman noted that what is different in South Africa is its status as a developing country with great inequalities. Also, South Africa has a freestanding and enforceable constitutional right to access health care services.

Looking first at constitutional health rights in context, Ms Forman said that apartheid impoverished black South Africans and created inadequate social and economic infrastructures including those for health. Health rights were included in the constitution along with rights to food, water, education, housing, etc that were all intended to address inequalities. In addition, the Bill of Rights provides enforceable socio-economic rights to health care services, food, and water, etc.

There are a number of health rights in the constitution including that found in s. 27, which states that everyone has the right to have access to health care services, including reproductive health care. It also provides that the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of this right to health care. This right is very vague but guidance has emerged from the courts.

_Soobramoney v Minister of Health_ (1996): This case found that a hospital’s denial of dialysis to man did not breach s. 27. The man was in final stages of chronic renal failure. At that time the hospital had to ration, it had no hope of getting more funding. The Court held that the right to access health care services could not sustain all claims given existing
levels of poverty. It recognized that rationing access is necessary and maximizes a limited resource. In this case, there was no reason to think that the hospital’s guidelines were not rational.

_Grootboom_: In this case, the Court chose the standard of reasonableness to measure the state’s compliance with its constitutional obligations. This was a housing case but the interpretation bears directly on health. The Court found that reasonableness is to be decided on a case-by-case basis. The state’s primary obligation is to act reasonably to provide basic necessities to those who lack them. The reasonableness standards requires programmes to be comprehensive in dealing with all needs, it is unreasonable to exclude a significant segment of society, but there is a focus on the needs of poor who are dependent on the state for basic necessities and on urgent and desperate needs. It found that programmes must be balanced and flexible.

Ms. Forman reiterated the principle of progressive realization, which an obligation on the government to take steps towards meeting all basic needs in society, to progressively facilitate access – to examine and lower hurdles over time, act expeditiously and to meet effectively the goal of full realization. There is recognition that the state cannot do more than its level of resources permits; resources are thus an important determination of reasonableness.

To illustrate the national treatment policy in context, Ms. Forman discussed the controversies surrounding South African President Mbeki’s refusal to allow Anti-Retro Viral (ARV) medicines in the public sector. With respect to ARV medicines, the cost argument was increasingly unconvincing given price reductions on the drugs, international funding, legislative power to reduce costs, and the fact that poorer neighbouring countries were providing the treatment. She noted that ideology, not cost, motivated President Mbeki’s position that the country’s AIDS epidemic was scientific fiction.
A major issue was the State’s refusal to treat mother-to-child transmission of HIV. In
2000, the state agreed to a two-year pilot programme to prevent mother-to-child
transmission, but by 2001 not all sites were up and running and the state was blocking
access to nevirapine in the public sector. She then discussed the case of the Minister of
Health v. Treatment Action Campaign (TAC) in 2002. TAC argued before the Court that
delays and restrictions in treatment breach adults’ and children’s’ right to health. The
Court found that the government’s policy was rigid and inflexible; that it was
unreasonable to deny cheap, lifesaving drug needed urgently by children born to poor
women dependent on the state. The Court ordered the government to devise and
implement a comprehensive programme, immediately remove restrictions on nevirapine,
and make it available in the public sector.

The Court rejected the argument that the right to health entitles a minimum course of
health care services without resource limits; the government could only be expected to act
reasonably to provide access to socio-economic rights on a progressive basis. The Court
stated that its role was to guarantee that a democratic process was protected.

The impact on national AIDS policy was that poor and vulnerable women forced the
government to implement a national health programme. The State was held to equitable
and accountable health care, and irrational decision making was challenged. There was a
broader impact on the battle over the state’s refusal to treat the general population. In
August 2003 the government announced a national treatment programme. The TAC
decision showed civil society’s willingness to litigate and judicial willingness to order
appropriate policies. AIDS became politically damaging entering election year but
democratic accountability is an imperfect guarantee. The national treatment plan is
probably largely due to the TAC decision and effective mobilization. It is a remarkable
achievement that this happened. The scale of the epidemic contributed, but it also speaks
to the work of advocates/public support, and the use of civil freedoms.

With respect to the nature of the entitlement to access health care services, the s. 27
obligation focuses on accessibility; the positive obligation focuses on meeting the basic
needs of the poor. There is no automatic entitlement to health care, but to a reasonable policy that seeks to progressively meet needs. Cass Sunstein argues that rights are not individual entitlements, but an administrative law model that requires sensible priority setting and close attention to particular needs. Fitzpatrick and Slye argue that the appropriate individual remedy is to reasonable policies and may not provide tangible relief to applicants. Ms. Forman argues that in TAC the Court ordered specific and time bound compliance; so the right is a substantive entitlement to certain levels of health care, in which litigants can increasingly claim specific relief and is not simply an entitlement to sensible priority setting.

She noted that sometimes collective needs will take priority over individual needs. Individual claims are unlikely to be successful under the s. 27 right unless a cost benefit analysis comes out in their favour. Cost analysis looks at the human benefit. The approach requires courts to assess reasonableness of individual claims; collective interests cannot be privileged at expense of poor and vulnerable unless they are reasonable in terms of cost and impact; there is an implicit principle of proportionality; the nature of evidence presented will assist courts in balancing interests and assessing reasonableness.

In conclusion, she suggested that equity is an obligation, and not dependent on goodwill or historical contingencies; government is accountable for equity without cover of judicial deference or political unresponsiveness; the Constitution provides tremendous power for the powerless as illustrated by TAC; rights also entitle citizens to fair, rational and transparent health care decision-making; rights play a strengthening function in democracy by ensuring increased responsiveness of government to citizens.


They add to the culture of justification of constitutionalism and empower demands for justifiable policies. Overall, South Africa shows the transformative potential of rights – not simply textual, but dependent on effective use by civil society and enforcement by the courts.

Procedural or Substantive – Health Care Rights in the NHS:
Christopher Newdick, Reader in Law, University of Reading

Professor Newdick discussed (1) the meaning of “a comprehensive health service, (2) procedural rights, (3) the impact of human rights law and (4) statutory health care rights.

1. “A comprehensive health service”

The National Health Service Act 1977 (the “NHS Act”) contains a duty to promote a comprehensive health service (s. 1). The duty is to promote but not to provide; it is an aspiration, a target that will change over time. Hospital care is free; access to drugs is provided within the NHS except that there is a standing charge for prescriptions, with many exceptions for those who cannot afford it. The pyramid of the NHS has the Secretary of State at the top, Primary Care Trusts (PCTs) at the middle tier, and doctors/patients at the bottom. The s. 1 duty is immediately delegated to the 302 PCTs (in England and Wales). The general rule is that the Secretary of State does not interfere but maintains a statutory discretion to direct that PCTs do certain things. A vast majority of health care allocation decisions made in the NHS are made by the 302 PCTs. The government takes the view that they will not be involved in defining health care benefits:

To draw up a national list of treatments which will and will not be provided would be an exercise fraught with danger. No list could ever hope to accommodate the range and complexity of the different cases which clinicians face all the time (Govt. statement, 1995, Cmnd 2828, para 4).

2. Procedural Rights

With respect to judicial supervision of the NHS Act, judges’ involvement has created procedural rights only. This is not guaranteeing access to care but it is guaranteeing access to a procedure that will determine whether or not you get care. Thus, rationing is lawful
provided the Secretary of State has regard to the duty to promote comprehensive health care services. That is, it must touch everybody, if you exclude whole categories of treatment then it is no longer comprehensive. Professor Newdick explained the evolution of procedural rights in connection with claims to NHS care.

(a) Weak Procedural Rights

Until 1997 there was very weak procedural scrutiny. In 1988, the courts decided *Collier v. Birmingham*, in which a boy with a hole in his heart had a necessary operation cancelled three times. His parents went to court and the court said that it is not their role to allocate resources. The boy died. Professor Newdick argued that the court in this case was feeble. Their statement regarding allocation of resources was disingenuous – they were being asked to judge the propriety of the decision-making process, not the actual allocation. This was a very strong clinical case.

Similarly, in *R v Cambridge District Health Authority*, the girl in question had a resistant type of leukemia, and there was not a strong clinical case. The decision was made not to divert money from patients who would respond to treatment to her because she would suffer badly from the chemotherapy and yet still die. The court made a similar statement to that made in *Collier* but in this case the girl did not have a strong case. Again, however, there was weak procedural scrutiny by the courts. This was useless in terms of protecting rights, very feeble and weak. Professor Newdick noted, however, that in the same case in the High Court (trial court), the judge said there was a human rights issue. He said he wanted persuasive reasons why treatment was denied: “… the responsible Authority must…do more than toll the bell of tight resources.”

---

13 *Collier v Birmingham Health Authority* (1988, unreported)
14 *R v Cambridge District Health Authority, ex p B* [1995] 2 All ER 1
15 *R v Cambridge District Health Authority, ex p B* (1995) 25 BMLR 5, 16-17
(b) **Intense Judicial Scrutiny**

After 1997, a different style of court emerged and there were more persuasive reasons for refusing access to care. Some of these involved *macro-planning decisions*. It is true that the Secretary of State does not dictate policy throughout the NHS, however, the Secretary may introduce a discretionary policy. In the case of *R v N. Derbyshire HA, ex p. Fisher* (1998),\(^{16}\) the Secretary urged health authorities in a letter to think about introducing a certain drug for MS that would only be significantly clinically effective in 5% of cases. The Health Authority said that the drug would take away from its orthopedic budget and therefore refused to fund it. Fisher challenged the Health Authority’s right to say no in light of the Secretary’s letter. The case succeeded on the grounds that the court found a duty to take health service guidelines seriously and incorporate them into the decision-making process. Thus, judicial review did not guarantee access to the drug, but guaranteed that the decision would be taken again using the proper process. In reality, Health Authorities have always bowed to pressure in these cases and have reconsidered and found the money, usually by taking it away from someone else (disinvestment).

In *R v. NW Lancashire HA, ex p A, D & G* (1999),\(^{17}\) three transsexuals were refused surgery and won their claim to have the surgery. They applied to the Health Authority for transsexual surgery and were turned down. Again, they were not guaranteed treatment by the court decision, but the decision was thrown back to the Health Authority to make the decision again. The court recognized the need to set priorities, but it also said that a Health Authority cannot have a blanket ban on any treatment because that (the blanket ban) is irrational; rather there needs to be a procedure for assessing the nature and seriousness of each type of illness, etc. In every case, in order to recognize the rights of the individual, there needs to be a mechanism to review the individual circumstances and the way in which the decision was taken. In response to this case, the Berkshire Priorities Committee’s Ethical Framework was published to show the public

---

\(^{16}\) *R v N. Derbyshire HA, ex p Fisher* (1998) *8 BMLR* 77

how decisions would be made. The impact was not the same in other PCTs however. Again, the rights are to certain processes, not to actually receive care.

Sometimes cases involve micro-duties to individuals. In *R (ota F) v. Oxfordshire Mental Healthcare NHS Trust* (2002),\(^\text{18}\) it was held that if individual patients are refused the treatment they want, they are entitled to an individual review of that decision by a standing committee. This case says this process should not be judicialized; it should be informal where the patient normally does not have to be present. It just has to be impartial and fully informed.

*R (Burke) v General Medical Council (2004)*\(^\text{19}\) concerned the withdrawal of artificial nutrition and hydration (ANH) from incompetent patients. In order to discover what is in the patients’ best interests, it is necessary to look at ethical, social, and family considerations. The case says that withdrawing treatment from incompetent patients will often require court approval. Again, this case guaranteed access to a procedure, but not to the treatment itself.

### 3. Impact of Human Rights Law

None of these cases have had a direct impact on decisions regarding resource allocation. However, European law may change this. Early cases from the European Court of Human Rights found that resourcing cases cannot come to the courts. Human rights, if they have a role to play in health care, must have regard to what is universally achievable across the EU.

Never the less, there have been some indications of a very powerful role for human rights claims. For example, *D v United Kingdom* (1998)\(^\text{20}\) concerned an admitted patients’ right to necessary care. D was an immigrant from St. Kitts who attempted to smuggle crack-

---

\(^\text{18}\) *R (ota F) v Oxfordshire Mental Healthcare NHS Trust* (2002) *EWHC 535*

\(^\text{19}\) *R (Burke) v General Medical Council* (2004) 79 BMLR 126

\(^\text{20}\) *D v United Kingdom* (1998) 42 EHRR 149
cocaine into London. He was arrested, convicted and given a five-year sentence. It turned out that he had AIDS and, as a prisoner, he was treated under the NHS for this. When he was released, the government told him that he was to be deported and he sought to be admitted to NHS to receive ARV treatment in the UK, because he would not be able to receive this care back in St. Kitts. Is he entitled to receive care? The court said that, as an admitted patient, he was entitled to continue to receive care in the UK. This case represented a huge development, a real substantive right.

Similarly, in the “right to life” case of R (ota Burke) v General Medical Council (2004), a competent patient demanded that he continued to receive care. The patient claimant suffered motor neuron disease (also known as ALS or “Lou Gehrig’s Disease”). Many patients want to die at a certain point of this disease but this patient took the contrary view and wishes to live (even if sedated) for as long as possible. However, his doctor said he (the patient) could not make this decision, and that the doctors would make it for him. The Court said that the patient gets to decide on the basis that he was the best judge of his “best interests”.

Clearly, this case could have significant implications for the finite financial resources. What if clinical efficacy is doubtful, as in Auton, or R v. Cambridge Health Authority? In Shortland v. Northland Health, the New Zealand Court of Appeal denied the existence of a right to insist on treatment. It said:

To require the consent of the patient’s family to the cessation of a particular form of treatment, or to a decision not to give the patient a particular form of treatment, gives the family the power to require treatment to be given or continued irrespective of the clinical judgment of the doctors involved. The law cannot countenance such a general proposition. While the criterion may have been appropriate in the context of the proposed removal of a life-support system, as in the Auckland case, it cannot

---

21 R (ota Burke) v General Medical Council (2004) 79 BMLR 126
apply to a decision not to put a patient on long-term dialysis, following a period of assessment which demonstrated that long-term dialysis was clinically inappropriate (265).

As of March 2005, the *Burke* case has been taken to appeal and judgment is awaited.

A separate health care right has recently emerged in the shape of a right to an investigation of apparently *systemic* accidents. If there is a systemic failure in hospital, there is a substantive duty to conduct a full enquiry in order to protect future patients under the “right to life” provisions of article 2 of the European Convention on Human Rights.23

4. **Statutory Health Care Rights**

Governance of the NHS sometimes creates specific statutory health care rights which can broadly be divided into two categories: procedural rights and substantive rights.

(a) **Procedural Rights:** A general statutory duty on PCTs to consult the public was created in 2002 but questions can arise as to who the “public” really is. Uncertainty surrounds the process of identifying a sound and representative cross-section of people and we are still experimenting with ways of doing so. In the county of Berkshire, PCTs are proposing to undertake focus groups and populations surveys and the NHS will have to learn from its experience. Importantly, the impact of public consultation is advisory only on PCTs (it is not mandatory).

(b) **Substantive Rights:** Professor Newdick noted two statutory substantive rights. The first concerns prescribing duties in primary care – primary care doctors have a duty under statutory regulations (which originated in 1948) to prescribe any drugs that are needed for the treatment of anyone he or she is treating. That is, they must prescribe on the basis of clinical need. Thus rationing in primary care seems to be unlawful in relation

23 *Powell v United Kingdom* (2000) 6 EHRLR 650
to prescribing duties. The difficult word is “needed”, what does this mean? A lot of clinical discretion is involved in this regard. There is an exception where drugs are on the “black list” (cannot be prescribed in the NHS) or the “grey list” (may only be prescribed in restricted circumstances). The regulations were considered in a case involving Viagra – is it clinically “needed”? The Secretary of State wrote to GPs and instructing them not to prescribe Viagra since, he said, erectile dysfunction is not a life-threatening condition.\textsuperscript{24} The drug company sought judicial review, saying that the regulations made clear that it is for GPs to decide on the basis of clinical need, not the Secretary of State. The Court found the letter to be unlawful/void/of no legal effect for contradicting the regulations. Thereafter the drug was properly placed on the “grey list” by Parliament so that, today, it can be prescribed but only in limited circumstances only.

The second statutory substantive duty arises from the National Institute for Clinical Excellence (NICE). If NICE recommends the use of a particular drug by means of a “Technology Appraisal Guidance”, PCTs are duty bound to fund the cost of the drug. There are about 120 products so far that have been recommended by NICE. The recommendations are not binding on doctors, but if a doctor prescribes one of the recommended drugs then the NHS is duty-bound to pay for it. Again, this is a substantive right created by a statute. There have been arguments that this diverts resources from treatments that have not gone through NICE and, within finite budgets, requires “disinvestment” from other patients – a process which takes place without sufficient discussion or debate. NICE is conscious of these misgivings and, encouraged by the WHO, is seeking to improve its processes.

In conclusion, contemporary health care debate emphasizes the rights of individuals, but it is important not to lose sight of the concept of public health and the needs of communities. Within fixed financial budgets, hard choices will always be required. Recent developments in the NHS have improved some aspects of the procedural rights of patients,

\textsuperscript{24} R v Secretary of State, ex p Pfizer [1999] Lloyds Rep Med 289
but the delicate balance between “public” and “private” requires greater transparency in
decision-making and more sophisticated public involvement in the process. Both present
significant challenges in the UK.

Panel Discussion:
Professor Lorraine Weinrib (Chair), Professor Rebecca Cook, and Dr. Nancy Walton

Professor Weinrib called on each of the panelists to present their responses to the
presentations.

Cook: Professor Cook gave a brief overview of developments in international human
rights law with respect to the right to health care. The right to health care and fairness in
the allocation of health services has a lot of currency in international health circles.
Health is affected by:

- clinical services,
- health systems and,
- the underlying socio-economic conditions and other determinants of health.25

Medicine focuses on improving the health of individuals in the context of clinical services
to treat physical and to a lesser extent mental illness. Health systems go beyond clinical
services to determine how the health of populations can be maximized. Health systems
use epidemiological and health systems research to plan and implement health
interventions that emphasize prevention of diseases and promotion health. Social science
research has underscored the importance of underlying conditions and determinants, and
the importance of socio-economic, gender and racial factors in affecting health outcomes.

Courts continue to play a significant role in regulating the delivery of clinical services, by
ensuring respect for patient autonomy26 and, for example, patient confidentiality.27 Recent

25 Rebecca J. Cook, Bernard M. Dickens and Mahmoud F. Fathalla, Reproductive Health and
Human Rights: Integrating Medicine, Ethics and Law, 2003 Oxford: Clarendon. 218-221, 256-259
26 Reibl v. Hughes (1980), 114 D.L.R. (3d) 1 (Supreme Court of Canada)
efforts to reform health care are now requiring courts to scrutinize the fairness of
decisions at health system levels; that is, of choices of ministries of health, in allocating
scarce health resources. Just as courts have developed an important body of jurisprudence
and norms regulating the delivery of clinical care, so too is their role significant in
developing norms and standards at the health systems levels, especially in the fairness of
allocating scarce health resources.\textsuperscript{28}

National courts spanning the globe, from Australia to Venezuela, from South Africa to
Canada, are now acting as forums for public deliberation on health care rationing.
International human rights tribunals and committees are also considering questions of fair
access to health care. Whether before national or international courts, governments are
now required to justify the choices they have made in allocating public resources,
according to human rights principles. They have to explain the criteria that underpin
their decisions, and satisfy the courts that they have considered all interests, but only
relevant interests. Courts are requiring greater transparency in decision making, whether
it be in scientific review, or in fairness in the process of review. Generally in the area of
allocation of health care resources, courts are moving from a mode of deference to the
executive branch of government to a mode of deliberation.\textsuperscript{29}

Common complaints against government allocation decisions concern those of
discrimination in access to care, or denied or delayed access. The grounds on which
discrimination claims are made include sex,\textsuperscript{30} race,\textsuperscript{31} health status or disability,\textsuperscript{32} marital

\textsuperscript{27} W v. Egdell [1990] 1 All E.R. 835 (English Court of Appeal).
29(3) 1-27
\textsuperscript{29} K. Syrett, Deference or Deliberation: Rethinking the Judicial role in the Allocation of Healthcare
Resources, Proceedings of the 15\textsuperscript{th} World Congress on Medical Law, Congress Proceedings, 2004,
Sydney Australia, 190-198.
\textsuperscript{30} New Mexico Right to Choose/NARAL v. William Johnson, Secretary of the New Mexico Human
Services Department, 126 N.M. 788, 792 (1999) Supreme Court of New Mexico (the state’s
prohibition of funding for medically necessary abortions denies Medicaid-eligible women equality
under the law because it does not apply the same standard of medical necessity to men and
women).
status, sexual orientation. Where there is no discrimination in access to care, courts are being asked to decide whether denial of basic health care is a form of inhuman or degrading treatment, or whether it infringes rights to life or security, or offends complainants' right to health care. This has arisen in such areas as fair access to

31 Linton v. Tenn. Community Health & Environmental, 779 F. Supp. 925, affirmed 923 F.2d 855 (6th Cir. 1981) (bed certifications policies with adverse disparate impact on racial and ethnic minorities held discriminatory and in violation of title VI of the Civil Rights Act and the Medicaid statute).
32 Eldridge v. British Columbia (Attorney General) (1977), 151 D.L.R. (4th) 577 (The Supreme Court of Canada decided that failure to provide funding for sign language interpretation that would equip hearing-impaired patients to communicate with health services provides in the same way that unimpaired patients can constitutes discrimination in violation of the Canadian Charter on Rights and Freedoms); Auton (Guardian ad Litem of) v. British Columbia (Attorney General) (2002) 220 D.L.R. (4th) 411 (B.C.C.A.) (The British Columbia Court of Appeal upheld British Columbia Supreme Court's decision in finding that governmental failure to provide services for autistic children constituted discrimination on grounds of disability in violation of the Canadian Charter on Rights and Freedoms, and could not be said to be reasonably justifiable.) An appeal is pending before the Canadian Supreme Court; Cameron v. Nova Scotia Attorney General (1999) D.L.R. (4th) 611 (The Nova Scotia Court of Appeal decided that Nova Scotia's refusal to fund infertility services, while discriminatory, was justified due to costs and lack of proven effectiveness.)
34 Korn v Potter (1996) 134 DLR (4th) 437 (denying a lesbian woman artificial insemination is a violation of her right to nondiscrimination on the ground of sexual orientation) Supreme Court of British Columbia.
38 Minister of Health v. Treatment Action Campaign (No 2) 2002; Cruz Bermudez, et al v. Ministerio de Sánidad y Asistencia Social (MSAS), Case No. 15789, 1999 (Pursuant to the rights to life and health, the Venezuelan Supreme Court required the Ministry of Health to provide the medicines prescribed to all HIV positive Venezuelans by government doctors, cover the cost of HIV blood tests in order for patients to obtain the necessary anti-retroviral treatments and treatments for opportunistic infections, develop the policies and programs necessary for treatment
emergency care,\textsuperscript{39} palliative care,\textsuperscript{40} treatment for HIV/AIDS,\textsuperscript{41} kidney failure\textsuperscript{42} and care for prisoners.\textsuperscript{43}

Some of these judgments rely on the Right to the Highest Attainable Standard of Health, protected by the International Covenant on Economic, Social and Cultural Rights (the Economic Covenant),\textsuperscript{44} which Canada has ratified. The Covenant’s monitoring body, the Committee on Economic, Social and Cultural Rights (the Economic Committee) has developed a General Comment on the Right to the Highest Attainable Standard of Health.\textsuperscript{45}

This Comment on the Right to Health provides guidance to Covenant’s member countries in reporting to the Economic Committee on what they have done to protect this right to satisfy the criteria of what are described as the four A’s. These criteria require that health

\textsuperscript{39} Paschim Banga Khet Mazdoor Samty v. State of West Bengal (1996) 4 SCC 37; (1996) 3 SCJ 25, digested in (1998) 2 Commonwealth Human Rights Law Digest 109. (The Supreme Court of India held that the right to life protected by Article 21 of the Indian Constitution was breached when various government hospitals denied a complainant emergency treatment for serious head injuries.)

\textsuperscript{40} D. v. United Kingdom (1997), Eur. Ct. H.R., 24 E.H.R.R. 423. (The European Court of Human Rights held that the U.K. could not deport a convicted drug trafficker, who was at a very advanced stage of terminal and incurable AIDS, to his native country where he would not receive appropriate care would constitute inhuman treatment contrary to Article 3 of the European Convention on Human Rights.)

\textsuperscript{41} Minister of Health v. Treatment Action Campaign (No 2) 2002.

\textsuperscript{42} Soobramoney v. the Minister of Health, KwaZulu Natal, 1998 (1) SA 776. (The Constitutional Court of South Africa held that the state was not constitutionally required to provide long-term renal dialysis treatment because the claimant fell outside the guidelines for medical eligibility and the exercise of the right to health, protected by Section 27 of the South African Constitution, can be reasonably limited by lack of resources.)


services are: available, accessible, acceptable, and where they are not, to ensure that government is accountable to remedy deficiencies in availability, accessibility or acceptability in health care delivery.

This General Comment explains that “States parties have a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights enunciated in the Covenant, including essential primary health care.”\textsuperscript{46} It needs to be read in conjunction with General Comment on the Nature of States Parties Obligations under Article 2(1) of the Covenant, which reads in part:

“a State party in which any significant number of individuals is deprived of ... essential primary health care ... is, prima facie, failing to discharge it obligations under the Covenant. If the Covenant were to be read in such a way as not to establish such a minimum core obligation, it would be largely deprived of its raison d’etre. By the same token, it must be noted that any assessment as to whether a State has discharged its minimum core obligations must also take account of resource constraints applying within the country concerned. Article 2(1) obligates each State party to take the necessary steps ‘to the maximum of its available resources’. In order for a State party to be able to attribute its failure to meet at least its minimum core obligations to a lack of available resources it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”\textsuperscript{47}

\textsuperscript{46} General Comment 14, para 43; see AR Chapman, Core obligations related to the right to health, in A. Chapman & S. Russell, Core Obligations: Building a Framework for Economic, Social and cultural rights, Antwerp: Intersentia, 2002, 185-215.

The General Comment on the Right to Health, read together with the General Comment on State Obligations, require that states parties ensure that a minimum core of primary of health care is available, accessible, and acceptable.

*Walton:* Dr. Walton is currently involved in looking at decision-making in cardiology and the treatment of autism in Canada. What we are really talking about here is “values.” All the speakers today have at some point or another identified this, but it needs to be very specific. Whether we talk about priorities, evidence, whose voice is heard, how loudly we allow voices to be heard etc, it is all driven by values – of individuals, communities, institutions, national values. Evidence is value-driven, what we consider as evidence. Values, multiple priorities, complexities of reasons; these factors all drive decisions. When we ask whether it is appropriate for courts to make these decisions, we have to consider the burden it places on them. Some decisions are too hard for clinicians. Clinicians do for the most part try to make morally accountable decisions and encounter a lot of moral distress.

Other speakers have talked about ‘frustration’ and what it is. She suggests it is driven by a lack of publicly available evidence and reasons and lack of accountability and transparency in decision-making processes. There is availability of decisions but reasons behind those decisions are not always there and this drives a lot of the frustration. Norm Daniels looked at whether or not growth hormones for children are covered by private insurers in the US. He found that when it came to decisions as to whether hormones should be provided, they were given without reasons. However, when the decisions were reframed with reasons the parents were better able to accept the decision (the growth hormones were used to treat children with growth deficiencies, but were also being sought by parents whose kids were simply shorter than average and the parents thought the children would have social troubles; the latter were rejected by HMOs). The last issue in this part is the lack of forthrightness which speaks to process behind the outcome that should be presented; otherwise the public sees decisions as arbitrary. One of the problems
is that decision-making in health care is outcome focused, not process focused. In the medical world, we consider Random Controlled Trials (RCTs) as evidence; in a case like *Auton* there are very few RCTs, a lack of a gold standard of efficacy. Dr Walton suggested that there needs to be a different standard as to what constitutes evidence in a case like this.

With respect to *Chaoulli* and waiting list management, she noted that queue-jumping in Canada is anecdotal but it does exist. Research in waiting list management is outcome focused not process focused. There are tools out there that are not being used. Clinicians are using values to make decisions.

All these things show that we need more accountability and transparency. There is no perfect process. There will be different views on what outcome is fair; but we can at least find a process that everyone agrees with. It may be that people are better able to live with outcomes when this is the case. There should be publicly available decisions, with reasons behind them, a non-legal appeals mechanism, and some kind of enforcement. It is key to know who is enforcing this. If we show some consistency in decision-making this is where social learning can take place (rather than through media as it is now).

**Audience Discussion**

*Lisa Forman:* It should be noted the different levels through which we are approaching questions of decisions in health care. The basis for her exploration for the human rights framework in South Africa is international human rights. When you bring the international framework into the picture, it plays a different role in different countries. For example, in the US where there is no guarantee to health care, the resource question is a different one. Other important questions are those of international trade policies which may create inefficiencies in resource allocation. The perspective from which we all come (e.g., lawyer, ethicist, national, international, etc) is very determinant of the kinds of questions we ask.
Christopher Newdick: He has more faith in the procedural side of the debate rather than the substantive. Norm Daniels doesn’t talk about what the real criteria for decision-making should be. With respect to Berkshire’s code, they could be seen as empty, meaningless words, but how much further can you take it. You do not want it to be too specific either. In this regard, Nancy Walton talked about the question of informed consent. It is impossible to give complete informed consent but we can do our best to equip patients with the ability to make decisions. This is an analogy in that there will not be a perfect ethical framework, but they do speak to opening of the process and discussion which has not been open until now.

Rebecca Cook: With reference to Dr Walton’s concept of “social learning”, we as lawyers need to be very modest and think about all the forums that need to be used in the debate around health care, courts are not the only place and we should not rely on them to create a societal debate around fairness in health care. We need many more experiments like the code of practice from the Berkshire Authority.

Ms. Forman responded regarding social learning: The critical part of methodology in South Africa has been treatment awareness, and educating people about their right to claim treatment and the treatment. This comes back to the discussion around public participation and voice. When we talk about powerful interest groups capturing the process, what groups are we talking about? Powerful groups have captured processes behind closed doors.

One audience member referred to the UK’s experience with waiting times and noted that these did not seem to be much of a factor in the cases put forward. They questioned what the status is of guarantees to timely service and what efforts have been made in this regard that impact on rights to a broader array of services?

Professor Newdick responded that in a sense all the cases concern people being asked to wait. The UK government has issued numerous policy documents with targets that are not enforced with mandatory rights, but they are influential because NHS managers will
lose their jobs if they do not achieve the targets. There has been a huge investment of money as well as systems to make things work better in terms of waiting lists. There has been a fantastic improvement through incentives for managers. Professor Newdick noted, however, that the government has not tried expanding actual services offered after getting their fingers burned in the MS drug case. The exception is for cancer care where there are some very specific targets.

*Professor Maioni noted that in South Africa the courts are being used as a vehicle to have a voice in a political system that is problematic in terms of other kinds of voice. She asked the panel to comment on the different ways in which a legal framework and the courts offer voice and also the difference between developing and developed democratic nations.*

*Another audience member referred to public participation in the decision-making process and questioned where it has been successful. She also questioned how to keep powerful interest groups from capturing the process.*

With respect to public participation, Dr Walton talked about the process in Oregon. Her overall sense of the process there was that it did not work. She was involved in a project where they found that the public want to be involved in decision-making processes and have their voices heard, but they do not want to make the actual decisions.

Professor Marchildon noted that during the Romanow Commission, people wanted to be involved but in terms of the detailed resource allocation decisions they wanted their governments to be responsible and they wanted to ensure that the process is transparent. In terms of the process being captured by powerful interest groups, the Romanow Commission made sure that groups that wanted to make submissions had to answer more general questions which prevented them from simply putting forward their narrow position. They also had to agree to have their views made public on the website.

*A participant questioned how we get the public engaged in health and personal responsibility. She noted that this will have a significant impact on what we can afford and that it is therefore something of which we cannot lose sight.*
Professor Cook noted that in the area of women’s health care, she has wondered why the government has not been doing more in the area of prevention, that is, less costly treatment. Professor Newdick said that the government acknowledges this should happen but has been scared off from doing so; it is seen as patronizing to tell people how to live their lives.

Dr Walton suggested that it speaks to who provides the services; GPs don’t have time to do preventive medicine. Nurse practitioners are not always available, etc. She suggested that there is a conflicting message – the public needs more tools.

Professor Dickens noted that problems with preventive health care have to do with questions of evidence. The big difficulty in public health is proving how prevention works; it is hard to prove why something did not happen.

**SESSION THREE: OPEN DISCUSSION**

**CHAIRLED BY PROFESSOR GREG MARCHILDON**

Professor Marchildon suggested that the day’s conversation was predicated on certain assumptions of universality and fairness that do not exist in some countries such as the US. He said that in a conversation he had with someone in New York it was mentioned that if universality was ever to form a part of US health care it would have to come from the courts. We need to remember that universality is always limited, only some services fall within the basket. There are four themes that have arisen from today’s discussion:

1. Impact of recent judicial decision-making on individual and collective rights to health care services.
2. The nature of judicial intervention, the remedies, and the nuances as well as the sophistication of some of the remedies.
3. The impact on individual resource allocation decisions; the impact of the decentralized nature of the system.
4. The impact on the Medicare ‘basket’ – CHA services as defined provincially and territorially. This is the universal part of the Canadian system. We have 13
provincial baskets; there is a common core but some variation among them. There are other public health care baskets too, some federal direct services that impact First Nations and Inuit people, and workers’ compensation schemes.

Professor Marchildon then asked for the audience to provide some conclusions or penetrating questions:

Professor Jackman suggested that defining substantively what is in or out of the medicare basket is not doable, and noted there has been a lot of emphasis today on procedure rather than substance. But saying that, and designing processes in this context, is very complex and nobody seems to have done that yet.

Professor Marchildon responded that the big things in the basket are defined, but it is the small things that are undefined. Professor Jackman replied that she is interested in the big things, like cancer care, which people get once they are in the system even when they are dying anyway. Professor Marchildon agrees with Professor Jackman on one aspect – he too would like to see the basket. But he wants to see it done as a deliberate government decision; she wants the courts to play a greater role in increasing the size of the basket.

A participant said that he was struck to hear the word ‘rationing’ coming out. His impression is that rationing seems to be a taboo word in Canada, and questioned whether or not this is the case? If it comes to the point that governments feel they cannot put more money into health care, we may come to a time where governments might more openly have to make decisions about rationing. He questioned whether Canadians be as willing to accept governmental decisions to ration care as people seem to be in England? Or will they look to the American example and seek alternative approaches to getting care themselves.

Professor Marchildon responded that governments are not afraid of rationing. With respect to CHA services, they probably are because they do not want to be criticized for violating the CHA (and public embarrassment which that involves), but they have been cutting benefits quite continuously outside the area of CHA services. Provincial drug
plans are on an unsustainable track and governments have had to cut back. Rationing is not a common word but ‘coverage’ is, and cutting back benefits is quite common, it happened a lot during the 1990s. Provinces put on the brakes very hard during the 1990s. In that sense, governments are not afraid to do it. As to whether the courts will weigh in on the debate, Professor Marchildon thinks they are more likely to do so with respect to the national dimension, the CHA services, rather than the other.

Professor Maioni argued that we are in a ‘catch-22’ situation. We do not have a very clear definition of the Medicare basket. But the moment that basket becomes defined then we will want recourse to the courts to change it. By design the legislative drafters did not say exactly what would be covered. They used these vague terms to get around the question of having to decide exactly what should be covered. But once they are defined very specifically, the floodgates are open to legal recourse.

Professor Marchildon responded that he thinks she is right about national legislation but with respect to hospital legislation, the drafters were much more specific.

Another audience member said that if you look across the provinces, there is a high degree of specificity about what physician services are covered, what hospital services are covered, what drugs are covered in the formulary. One of the more useful contributions that this Medicare basket project can make is to map out the decision-mapping processes that happen at all levels (physician, regional, national) and to set out the available recourse mechanisms. Where is the public participation? When do the courts become involved? Nobody seems to have a very clear idea right now of what happens so this would be every valuable.

Professor Manfredi said that to the extent there are losers in any policy decision, the potential for litigation is there. During the day people have referred to the process and people being happier with the outcome if they like the process, but there are activists with specific goals in mind and they will not be happy unless they achieve a certain outcome. If they do not get that outcome, they will go to court regardless of the process that was used.
Another participant said she thinks the *Auton* case is a missed opportunity. Maybe if people had been looking for a procedural right, they would have been more successful. She suggests that people want to know they have been heard; she thinks the parents in *Auton* were angry because they felt they had not been heard. She suggests the courts are not well suited to these complex decisions and maybe there should be a limit on people’s ability to make claims. She suggests that there are models to be looked at but there needs to be an openness to do so.

Ms Forman raised the question of whether it is appropriate to allow litigation on health care because of the potential for adverse outcomes. She noted that there is no way to limit people’s unhappiness with outcomes. Maybe the question really is not whether we limit people’s access to make claims; but to look at the institutions that make decisions / look at the way those institutions address the claims. As to what Health Canada takes away from this; from the South African perspective and human rights perspective, its hard to define a basket, but less difficult to define principles that should define decision-making, perhaps Canada should not be looking at things just from a litigation perspective, but what do Charter values mean for the kinds of decisions that are made with respect to Medicare? A rights-based approach encompasses the notion that minimal rights contained in human rights law or constitutions can be developed in much more positive ways to provide guidelines for action, not at the litigation stage, but the ways in which governments design policies and programmes.

In response, Professor Marchildon said that if you have a principles based approach (and you could argue that the CHA provides this), and that provincial governments also had a patient charter setting out rights and responsibilities; and then say you are going to have a tribunal that will be cross-section of society and that it will interpret whether this legislation, which is principles-based, is properly applied. The tribunal would be looking at the processes. In return people would not be able to resort to litigation. This kind of approach has been taken in labour relations for example. He asked what people think about this?
Professor Jackman considered that parallel access to the courts would be required. She said the communities she works with would never agree to give up the ability to litigate Charter rights.

Professor Maioni argued that this is very different from other sectors such as labour management. We are talking about life and death situations. Models that work in other settings are not necessarily relevant. She is not sure that Professor Marchildon’s idea is better than the current system. Professor Marchildon responded that there is this model and others as well. The question is whether there are models other than what we have now.

An audience member referred to the Ontario Health Services Appeal & Review Board, which considers out-of-province treatment requests, and also the appeal system in Quebec. He would like to see consideration of how these other kinds of tribunals work.

Final words from Professor Marchildon:

→ There are existing models for provincial tribunals or similar bodies dealing with reviews. An inventory of these and an explanation of how they work would be quite useful given the current lack of knowledge in this regard.

→ It would be useful to map out the decision-making processes that are followed and the way in which they are communicated to the general public.

→ With respect to the issue more broadly of the role of individual vs. activists vs. well funded organizations vs. organizations that are poorly funded, distinctions need to be made and it needs to be understood better than it is. We need to understand what creates the litigation in the first place, not just the decision.
CLOSING REMARKS: PROFESSOR BERNARD DICKENS

Professor Dickens said that it had been a very full and rich day, and very long day! Professor Greg Marchildon has nicely summarized the thrust of the main points, but permeating the whole day has been the interaction of the resort to the courts by individuals and interest groups who want their preferences to be serviced; they want the whole system moved in service of their preoccupations. The challenge of the courts is to give effect to what has been described as the value of community, to look at the public interest and balance this against individual interests. Courts will not deliver all that claimants hope for and may not do all that their opponents fear. The question of public participation underlies this and the courts are not democratic institutions, governments at their best are. Issues that go to court involve questions of government accountability and effectiveness and it is right that lawyers and political scientists engage with each other. We know that much of the purpose of litigation is to curb effectiveness of government policies that individuals oppose; community can be caught in the cross-fire. Thus the day is necessarily incomplete in that it has framed but not resolved the conflict between individual and communal preferences.