

# Participation and Accountability: New Avenues for Human Rights Engagement with the Distribution of Health Resources in Canada\*

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## A) Introduction

Concern about the fair distribution of health resources in Canada is growing. International human rights norms appear to require Canada to move progressively towards a more equitable distribution of health-affecting resources. However, despite Canada's celebrated tradition of public health insurance promising comprehensive, universal, and accessible health care, Canada seems to be moving towards *less* equitable health resource distribution.

There are many challenges to undertaking human rights scrutiny of the distribution of healthcare resources in Canada. For years, opaque, disaggregated, and overlapping spheres of authority determined the funding, administration, and delivery of healthcare services, rendering any kind of meaningful analysis difficult.<sup>1</sup> In addition, human rights methodologies in Canada and internationally continue to wrestle with the content of social and economic rights (including the right to health) and the appropriate tools for enforcement. At the domestic level, judicial decisions under the *Canadian Charter of Rights and Freedoms*<sup>2</sup> suggest room for novel, collaborative approaches towards more meaningful constitutional social and economic rights enforcement, but these approaches are still in their infancy. At the international level, actors enforcing the human right to the highest attainable standard of health have, until recently, focused on universal minimum standards,<sup>3</sup> resulting in little discussion about the distribution of resources in a developed country like Canada. Despite these challenges, recent developments in health care governance in Canada, dovetailing with an emergent focus on governance and a social-determinants-of-health approach

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<sup>1</sup> See Colleen Flood, Duncan Sinclair & Joanna Erdman, "Steering and Rowing in Health Care: The Devolution Option?" (2004) 30 *Queens' LJ* 156 at 176.

<sup>2</sup> Part 1 of the *Constitution Act, 1982* being Schedule B to the *Canada Act 1982 (UK), 1982, c 11 [Charter]*.

<sup>3</sup> See Katharine Young, "The Minimum Core of Economic and Social Rights: A Concept in Search of Content" (2008) 33 *Yale J Int'l L* 113 at 130-31.

to the human right to health, may, together, open new possibilities for human rights analysis of the distribution of health-related goods and services in Canada.

In this chapter, I briefly analyze three interrelated trends in health and human rights and suggest the ways in which they might open new avenues for human rights scrutiny of the distribution of health resources in Canada. First, I note that courts may be more open to enforcing social and economic rights claims where legislative frameworks exist to facilitate meaningful scrutiny. Moreover, judicial actors may be willing to encourage and shape the development of such frameworks, even where they express—as they have from time to time—anxiety surrounding their institutional capacity to direct resource allocation. Second, at the international level, institutional and scholarly conceptions of the right to health are, likewise, expanding their gaze beyond monitoring states' health policies in search of violations and towards supporting processes designed to enhance democratic self-governance in relation to health. Finally, Canadian provinces have, over the last twenty years or so, moved towards allocating health care resources at the sub-provincial regional level, relying on participation-and accountability-enhancing governance features to drive more responsive resource allocation.

However, the turn towards participatory, accountable governance processes to ensure fairer distribution of health resources may not be entirely positive. For domestic and international human rights, as well as in healthcare governance itself, the development presents promise but also, risks. The chapter concludes with a brief discussion of the ways by which the agendas of scholars and activists might be affected by the turn towards governance as a means for driving the progressive realization of the right to health.

## **B) Human rights and distribution of health resources in Canada**

The international human right to health has a clear distributive dimension. The *International Covenant on Economic, Social and Cultural Rights* (ICESCR), to which Canada is a signatory, recognizes “the right of *everyone* to the enjoyment of the highest attainable standard of physical and mental health.”<sup>4</sup> Article 12(2)(d) of the ICESCR requires that states take all steps necessary for the “creation of conditions which would assure to *all* medical service and medical attention in the event of sickness.”<sup>5</sup> Article 2(2) of the ICESCR adds that the right to health is to be enjoyed “without discrimination,” and, in particular, without discrimination based on “social

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<sup>4</sup> *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, 993 UNTS 3, art 12(1), Can TS 1976 No 46 (entered into force 3 January 1976, accession by Canada 19 May 1976) [ICESCR] [emphasis added].

<sup>5</sup> *Ibid* at art 12(2d) [emphasis added].

origin, property, birth or other status.”<sup>6</sup> The United Nations Committee on Economic, Social and Cultural Rights (CESCR) adds, in its non-binding but influential General Comment No. 14 on the Right to the Highest Attainable Standard of Mental and Physical Health, that states have a “core obligation” to, *inter alia* “ensure rights of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable and marginalized groups” and “to ensure *equitable* distribution of all health facilities, goods and services.”<sup>7</sup>

Concern over fairness in the distribution of healthcare resources in Canada is high. The *Canada Health Act* (CHA) promises provinces funding for medically necessary hospital and physician services on the condition that provinces do not charge people for those covered services, effectively guaranteeing a core of free health care.<sup>8</sup> But the content of this core is contestable. Colleen Flood and colleagues, for example, have questioned the opaque and physician-interest-driven processes for determining procedures that qualify as medically necessary.<sup>9</sup> The set of services that ultimately qualify as medically necessary have been the subject of litigation and other critical attention.<sup>10</sup>

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<sup>6</sup> *Ibid* at art 2(2).

<sup>7</sup> Economic and Social Council, *Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000) The right to the highest attainable standard of health*, UNCESCROR, 22nd Session, 2000, UN Doc E/C/12/2000/4 (2000) at para 43 [*General Comment No. 14*] [emphasis added].

<sup>8</sup> *Canada Health Act*, RSC 1985, c C-6, ss 7-12.

<sup>9</sup> Colleen Flood, Carolyn Tuohy & Mark Stabile, "What's In and Out of Medicare? Who Decides?" in Colleen Flood, ed, *Just Medicare: What's in, What's out, How we decide* (Toronto: University of Toronto Press, 2006) at 15 [Flood, Tuohy, & Stabile, *Just Medicare*].

<sup>10</sup> Martha Jackman, "Charter Review as a Health Care Accountability Mechanism in Canada" (2010) 18 Health LJ 1; Cathy Fooks & Steven Lewis, "Romanow and Beyond: a Primer on Health Reform Issues in Canada" (Ottawa: Canadian Policy Research Networks, November 2002) at 14ff, 17ff, online: CPRN [www.cprn.org](http://www.cprn.org) [Fooks & Lewis, "Romanow and Beyond"]; Government of Saskatchewan Commission on Medicare, *Caring for Medicare: Sustaining a Quality System* (Regina: Policy and Planning Branch Saskatchewan Health, 2001) at 55, online: Government of Saskatchewan [www.health.gov.sk.ca](http://www.health.gov.sk.ca) [The Fyke Commission]; National Forum on Health, *Canada Health Action: Building on the Legacy. Vol. I: Final Report* (Ottawa: Minister of Public Works and Government Services, 1997) at 7 & 13, online: Health Canada [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca) [*Canada Health Action*]. See also *Ontario Human Rights Commission & Hogan et al v Ontario (Minister of Health and Long-Term Care)* (2006), 58 CHRR 317 at paras 104-5, 130, 152 & 182 [Hogan]; *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78 at paras 13, 30 & 32 [Auton].

Further, as suggested by both scholars and a succession of reports that investigated the state of millennium-era publicly-funded health care in Canada,<sup>11</sup> overall distribution of health care resources in Canada may be slowly growing *less* equitable as a greater proportion of health services used by Canadians falls outside the ambit of the *Canada Health Act's* user fee ban. For example, mental health care, palliative care, post-acute care, home care, and pharmaceuticals, among numerous other services, are increasingly relied upon, yet their accessibility is not assured by the *Canada Health Act's* user fee ban.<sup>12</sup> These non-*CHA*-covered health services are funded (or not) at provincial discretion. The related question about the relationship between health care services and social determinants of health raises similar difficulties, as the *CHA* generally addresses curative and not preventative care.<sup>13</sup> In addition, wait times and other non-financial barriers to access have

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<sup>11</sup> See for example Vandna Bhatia, "Social Rights, Civil Rights, and Health Reform in Canada" (2010) 23 *Gov 37* at 44, 49, 53 & 54 (this user fee ban under the *CHA* effectively prohibits service providers from charging fees for government-insured services) [Bhatia].

<sup>12</sup> See for example The Fyke Commission, above note 10 at 34 (discussing palliative care in the Canadian Health Care System); *Canada Health Action*, above note 10 at 8 & 14 (discussing post-acute care in the Canadian Health Care System); Carol Donovan, "Overview of Policy Issues in Finding and Financing Home and Community Care" (Presentation delivered at the Home and Community Care Policy Meeting, Health Canada, Toronto, 2000) (discussing home care in the Canadian Health Care System); Fooks & Lewis, "Romanow and Beyond," above note 10 at 9 (discussing pharmaceuticals and mental health care in the Canadian Health Care System).

<sup>13</sup> See Carolyn Hughes Tuohy, "The Hedgehog and the Fox: Glouberman and Marmor on 'Healthy Public Policy'" (2007) 2:1 *Health Economics, Policy and Law* 107 at 107 & 110 (defining social determinants of health as "that broad set of socio-economic factors well beyond the purview of health care systems, strikingly correlated with socio-economic status, that influence the health of populations").

received increasing attention, particularly following the wave of reports on publicly funded health care in Canada.<sup>14</sup>

In this context, it is fair to conclude that the introduction of the single-payer model only initially moved towards equalizing the distribution of health care resources in Canada. When the *CHA* was introduced, health care resources were understood as being comprised almost entirely of hospital and physician services and all such services were provided at no cost to the user. But over time, a greater proportion of health-related expenditures have come from supplementary insurance plans or out-of-pocket payments for services that fall outside the *CHA*, particularly for those with chronic illness and disabilities. Vandna Bhatia calls this the failure of governments to expand Medicare to include the large and growing number of services that fall outside its ambit a “passive policy drift,” arguing persuasively that it has called into question the solidarity claims of Medicare’s advocates.<sup>15</sup> Certainly, it has become increasingly difficult to claim that health care distribution is driven by need rather than ability to pay.

Finally, an overarching concern in each of these areas is accountability: overlapping and unclear lines of responsibility for decisions affecting the provision of health services have made it difficult to identify the goals of health-related spending, whether decisions are achieving desired goals, and who is responsible where they do not.<sup>16</sup> Meanwhile, the internationally recognized human right to health demands progress towards needs-based health resource distribution. Neither the Canadian and Provincial/

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<sup>14</sup> Commission d’étude sur les services de santé et les services sociaux, *Emerging Solutions. Report and Recommendations* (Québec: Government of Quebec, 2000) at 2, 6, online: CPRN [www.cprn.org](http://www.cprn.org) [The Clair Commission Report]; Fooks & Lewis, “Romanow and Beyond,” above note 10 at 18; The Fyke Commission, above note 10 at 35; *Canada Health Action*, above note 10 at 5; Ontario Health Services Restructuring Commission, *Looking Back, Looking Forward. A Legacy Report* (Toronto: The Ontario Health Services Restructuring Commission, March 2000) at 2ff.; Premier’s Advisory Council on Health, *A Framework for Reform* (Edmonton: Premier’s Advisory Council on Health, Government of Alberta, December 2001) at 4, online: Legislative Assembly of Alberta [www.assembly.ab.ca](http://www.assembly.ab.ca) [The Mazankowski Report]; Premier’s Health Quality Council, *Health Renewal* (Saint John, The Premier’s Health Quality Council, Government of New Brunswick, 2002); Senate, Standing Committee on Social Affairs, Science and Technology, *The Health of Canadians- the Federal Role. Volume Six: Recommendations for Reform* (Ottawa: Government of Canada, 2002) at 10 & 11, ch 5, online: Parliament of Canada [www.parl.gc.ca](http://www.parl.gc.ca) [The Kirby Report].

<sup>15</sup> See Bhatia, above note 11, at 46 (observing that “the burden [of the growing private component of health care] is heaviest for those who were the most vulnerable: the very sick or those with chronic illnesses, many of who are on fixed incomes and lack supplementary insurance).

<sup>16</sup> See for example Timothy Caulfield & Nola Ries, *Accountability in Health Care and Legal Approaches* (Ottawa: Canadian Policy Research Network, Document 28717, May 4 2004) at 7, online: CPRN [www.cprn.org](http://www.cprn.org).

Territorial governments nor the bodies charged with human rights monitoring and enforcement—judges, UN bodies, human rights commissions—have adequately addressed the requirements of equitable distribution in terms of human rights.

### 1) Domestic-level judicial scrutiny of health care allocation

At the domestic level, judges have been somewhat cautious about intervening in what they may consider to be legislative and policy decisions about health care allocation challenged under the *Charter* or provincial human rights legislation. In challenges to health care distribution decisions under section 15(1) guarantee of equality and section 7 guarantees of life and security of the person, the Supreme Court has affirmed the constitutional guarantee of non-discriminatory access to publicly funded health services.<sup>17</sup> The Court has also affirmed a right against state interference with individual health-seeking behavior.<sup>18</sup> The reasonableness of government decisions in relation to allocation, however, has not yet been subjected to meaningful *Charter* scrutiny.

The high-water mark in challenges to health allocation under section 15 (1) of the *Charter* is the decision in *Eldridge v British Columbia (Attorney General)*. In that case, the Supreme Court held that a provincial government's failure to provide sign language interpretation where necessary to ensure equal access to health care violated the constitutional equality guarantee enshrined in section 15(1) of the *Charter*.<sup>19</sup>

By 2004, the Supreme Court appeared to circumscribe somewhat the reach of *Eldridge* in the context of healthcare priority-setting. In *Auton (Guardian ad litem of) v British Columbia*, a unanimous Court held that failure to provide a particular behavioral treatment to children with autism did not violate the Charter's equality guarantee.<sup>20</sup> The Court reasoned that section 15 (1) protected only equal access to benefits "provided by law;" since the province had decided not to fund the service sought by the appellants, there could be no discrimination.<sup>21</sup> The Supreme Court in *Auton* did go on to preclude funding decisions with a "discriminatory purpose, policy or effect."<sup>22</sup> This decision set a high threshold for discrimination in health care

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<sup>17</sup> *Eldridge v British Columbia (AG)*, [1997] 3 SCR 624 [*Eldridge*].

<sup>18</sup> *Auton*, above note 10 at para 46; *Chaoulli v Quebec (AG)*, 2005 SCC 35 [*Chaoulli*]; *Canada (AG) v PHS Community Services Society*, 2011 SCC 44.

<sup>19</sup> *Eldridge*, above note 17.

<sup>20</sup> *Auton*, above note 10.

<sup>21</sup> *Ibid* at para 46.

<sup>22</sup> *Ibid* at para 41.

funding allocation decisions, however: absent a “readily identifiable” discriminatory purpose or policy, an allocation decision could generally only be considered discriminatory where it failed to comport with the overall scheme of its own governing legislation.<sup>23</sup> Since the federal and provincial laws establishing public health care in Canada create only a partial-coverage scheme, the exclusion of some treatments from coverage would not engage the equality right. The decision appears, at first blush, to narrow the scope for scrutiny of discriminatory impact in health care allocation.<sup>24</sup>

However, the insistence in *Auton* that section 15 is not engaged by health service funding allocation decisions because such funding is discretionary seems somewhat at odds with section 15 jurisprudence. In *Gosselin v Quebec*, for example, the Court scrutinized a legislative exclusion from benefits more closely than it did in *Auton*.<sup>25</sup> *Gosselin* was a challenge to a law that denied full welfare benefits to people under thirty who failed to participate in a workfare program. The Court did not follow the *Auton* logic that the choice to exclude people under thirty who failed to participate in workfare meant that there was no benefit provided to them by law, and, thus, no basis for a claim of discrimination. Instead, the analysis progressed further to consider whether the scheme was discriminatory in substance. Ultimately, the court held that there was no discrimination on the basis that the denial affirmed the dignity of those under thirty by underscoring the legislature’s confidence in their ability to work for a living. Perhaps the *Auton* Court’s refusal to engage in substantive consideration of effects-based discrimination in the context of health care allocation decisions reflects a generalized anxiety around judicial review of health care allocation.

Moreover, and perhaps more importantly for the purposes of this discussion, *Auton* might have been understood with reference to the dialogical relationship between *Charter* and legislative norms. Commenting on *Auton*, Greschner and Lewis suggest that courts can play a role in encouraging more evidence-based allocation and in signaling problems with governmental decision-making. Specifically, they suggest that courts should demand that governments consider the nature of the condition, the effectiveness of treatment, and cost in making allocation decisions in order to encourage better transparency and rationality in health care allocation decisions.<sup>26</sup>

The dynamism that Greschner and Lewis call for is reflected somewhat the judicial scrutiny of health resource allocation under section 7 of the *Charter*. Although at first glance, recent section 7 jurisprudence might

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<sup>23</sup> *Ibid* at para 42.

<sup>24</sup> See Mel Cousins, “Health Care and Human Rights after *Auton* and *Chaoulli*” (2009) 54:4 McGill LJ 717 [Cousins]; Martha Jackman, “Health Care and Equality: Is there a Cure?” (2007) 15 Health LJ 87 [Jackman, “Health and Equality”].

<sup>25</sup> *Gosselin v Quebec (AG)*, 2002 SCC 84 [*Gosselin*].

<sup>26</sup> Donna Greschner and Steven Lewis, “Auton and Evidence-Based Decision-Making: Medicare in the Courts” (2003) 82 Can Bar Rev 501 at 523 & 525.

appear to support a move towards a free-market rather than a redistributive agenda, it also reflects judicial willingness to demand government accountability in relation to health policy and finance. For example, in *Chaoulli v Quebec (Attorney-General)*<sup>27</sup> the Supreme Court accepted, by a four-to-three majority, that a provincial prohibition on obtaining private health insurance for publicly insured services violated the *Quebec Charter of Human Rights and Freedoms*' "right to life, and to personal security, inviolability, and freedom."<sup>28</sup> Three of the majority judges also ruled that the prohibition violated the similar life and security of the person guarantee enshrined in section 7 of the Canadian *Charter*. The government had defended the legislation as a means of protecting the public system. The majority reasoned that the insurance ban, in conjunction with excessive wait times for covered services in the public system, forced Quebecers onto unduly long wait lists, thus compromising their ability to attend to their own health needs. While *Chaoulli* can be criticized for unjustifiably supporting a negative-rights vision of the constitution,<sup>29</sup> it might also be understood as call for better accountability.<sup>30</sup> The majority of the Court relied on the notion that the private insurance ban was unnecessary because some jurisdictions managed to have thriving public health systems without it. Many scholars, however, disagreed with the Court's appreciation of the facts on this point.<sup>31</sup>

This paper proposes that a legislative framework geared towards providing more meaningful accountability in relation to legislatively-set goals might generate judicial forbearance where policies are demonstrably moving towards those goals and may, indeed, help justify a discrimination claim where policies are failing to achieve them. For example, a legislative requirement to assess whether the exclusion of under-thirties from welfare, in

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<sup>27</sup> *Chaoulli*, above note 18.

<sup>28</sup> *Charter of Human Rights and Freedoms*, RSQ c C-12, s 1.

<sup>29</sup> See Sujit Choudhry, "Worse than Lockner?" in Colleen Flood, Kent Roach & Lorne Sossin, eds, *Access to Care, Access to Justice: The Legal Debate over Private Health Insurance in Canada* (Toronto: University of Toronto Press, 2005) at 75 [*Access to Care, Access to Justice*].

<sup>30</sup> See for example David Hadorn, "The Chaoulli Challenge: Getting a Grip on Waiting Lists" (2005) 173:3 Can Med Assoc J 271 (the author suggests that Chaoulli be viewed as an encouragement to develop objective criteria for the limits of what public health care might guarantee).

<sup>31</sup> See Martha Jackman, "The Last Line of Defence for [Which?] Citizens: Accountability, Equality and the Right to Health in *Chaoulli*" (2006) 44 Osgoode Hall LJ 349 at 357; Hamish Stewart, "Implications of *Chaoulli* for Fact-Finding in Constitutional Cases" in *Access to Care, Access to Justice*, above note 29 at 211; Charles G Wright, "Different Interpretations of 'Evidence' and Implications for the Canadian Healthcare System" in *Access to Care, Access to Justice*, above note 29 at 223 (all criticizing the Supreme Court's failure to attend to expert evidence justifying the insurance ban, Wright calling it "utterly inexplicable").

fact, resulted in better integration into the work force might have prevented courts from accepting the government's bare assertion in *Gosselin*. Similarly, a legislative framework providing for accountability between measures like the private insurance ban and the government's ability to provide a universal, accessible health care system might have made it more difficult for the court to consider the ban as arbitrary.

Distribution-related questions have been more squarely addressed under human rights legislation, where legislation has supported a requirement of government accountability.<sup>32</sup> For example, in *Ontario Human Rights Commission & Hogan et al v Ontario*, claimants argued that the removal of sex reassignment surgery (SRS) from the list of medical services covered under the province's health insurance scheme discriminated on the basis of both sex and disability.<sup>33</sup> The Ontario Cabinet, in the late 1990s, was engaged in a "tightening and modernization" process designed to save the province \$50 million a year in health care. Although the service cost the government only \$123,891.81 per year, the Ontario Cabinet removed SRS and a number of other services from the schedule of publicly insured benefits. A number of SRS recipients challenged the removal.

Ontario human rights legislation shifts the burden to the respondent to justify any actions that create effects-based discrimination on prohibited grounds of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, marital status, family status or disability.<sup>34</sup> An alleged discriminator must thus explain why a rule or measure with discriminatory effects is reasonable and *bona fide* in the circumstances and show that the respondent cannot accommodate the claimant without incurring undue hardship.<sup>35</sup> This arguably represents a broader equality protection than is available under section 15 (1) of the *Charter*. Finally, the state action requirement that was used as the basis for denying the applicability of equality analysis under the *Charter* in *Auton* is absent here: the equality guarantee applies to all "services, goods and facilities," publicly or privately delivered.<sup>36</sup> The result is that the analysis under the *Ontario Human Rights Code* proceeds quickly to an examination of the reasonableness and *bona fides* of the rule or decision.

What is interesting about the *Hogan* decision is that both the majority and the dissenting judges went on to examine, and disagree on, whether the processes of de-listing rendered that decision reasonable and *bona fide* in the

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<sup>32</sup> Cousins, above note 24 at 732.

<sup>33</sup> *Hogan*, above note 10 at para 3.

<sup>34</sup> *Human Rights Code*, RSO 1990, c H 19, ss 1, 11 [*Human Rights Code*].

<sup>35</sup> *British Columbia (Public Service Employee Relations Commission) v British Columbia Government and Service Employees' Union (BCGSEU)*, [1999] 3 SCR 3 at para 22.

<sup>36</sup> *Human Rights Code*, above note 34.

circumstances. The majority held that since de-listing was a cabinet decision, no justification was required,<sup>37</sup> effectively undermining the impact of the shift of the justificatory burden to the government. In any event, it held, there was sufficient evidence to suggest that sex reassignment surgery was not “money well-spent.”<sup>38</sup> The majority supported this view mainly with reference to the statements of Dr. Dickey who, ironically, was an expert witness for the claimants and one of the primary supporters of maintaining SRS on the schedule of insured services.<sup>39</sup> Dr. Dickey had conceded that not everyone was always satisfied with the results of SRS, and that some people with gender identity disorder, “go away and learn to live with it.”<sup>40</sup> The majority declined to attribute any weight to the “turbulent political wrangling” that surrounded the delisting.<sup>41</sup> It also rejected the contention that the de-listing had taken place without sufficient consultation with the Ontario Medical Association, Gender Identity Disorder Specialists, and the transsexual community.

The dissent had a different appreciation of the facts. It found little reason to question the effectiveness of SRS for people with the most profound Gender Identity Disorder.<sup>42</sup> More important for the present purposes, however, was the dissenting judge’s attention to processes of delisting. At the time the decision to de-list was made, the dissenting judge determined that there was no evidence that the government had any medical, policy, or budgetary rationale, or any other non-discriminatory reason for this decision.<sup>43</sup> She also placed heavy emphasis on the fact that while other delisting decisions were made pursuant to a “tightening and modernization review” process that included extensive consultation with medical experts and publicity on the Ministry of Health’s website, de-listing of SRS was undertaken without any meaningful consultation.<sup>44</sup> In her view, the “way in

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<sup>37</sup> *Hogan*, above note 10 at para 109.

<sup>38</sup> *Ibid* at para 105.

<sup>39</sup> *Ibid* at para 62.

<sup>40</sup> *Ibid* at para 105.

<sup>41</sup> *Ibid* at para 108.

<sup>42</sup> *Ibid* at para 260 (“... it is a legitimate, international, medically-recognized, effective, non-cosmetic treatment of longstanding for transsexuals who have the most profound [gender identity disorder]”).

<sup>43</sup> *Ibid*.

<sup>44</sup> *Ibid* (indicating that the delisting of SRS was not accompanied by the same level of consultation as other delisting of services, due to a discriminatory and arbitrary decision-making process; in light of the seriousness of this disability, there was “no medical, policy or budgetary rationale, or any other non-discriminatory reason for this decision”).

which sex reassignment surgery was de-listed was so reckless, particularly when compared to the way in which other services were reviewed and de-listed at the same time, that it constituted an abuse of power.<sup>45</sup> The decision was taken in bad faith and, as a result, constituted direct discrimination.

The *Hogan* story, and most notably the dissent's attention to processes surrounding allocation decisions, suggests that legislative or judicial demands for better transparency and consultation may helpfully play a role in addressing power relations in determination of health policy, and particularly decisions affecting the distribution of resources.<sup>46</sup> In a context where governments are required to justify health care decisions with reference to standards for participation and accountability, these power relations might be more open to judicial scrutiny than when the focus is on the substance of the decision alone.

Take, for example, the decision to delist hearing aid evaluations in Ontario, which was considered by the Ontario Superior Court in *Shulman v College of Audiologists and Speech Language Pathologists of Ontario*.<sup>47</sup> In that case, Perdu J determined that the delisting did not violate section 15 of the *Charter*, reasoning in much the same way as the Chief Justice in *Auton* that the ambit of the equality guarantee was limited to equal access to existing services and could not affect the scope of those services.<sup>48</sup> Justice Perdu stated that “in delisting hearing aid evaluations and re-evaluations, the hearing impaired are treated no differently from others who must pay for medications, maintenance of their prosthetic devices, wheelchairs, and or eyeglasses.”<sup>49</sup>

This decision has been criticized, like *Auton*, for relying on formal, decontextualized conceptions of equality.<sup>50</sup> As Jackman has pointed out, the de-listing of hearing aid evaluations would clearly have a disproportionately adverse effect on the health and well-being of people with impaired hearing,<sup>51</sup>

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<sup>45</sup> *Ibid* at para 444.

<sup>46</sup> See Martha Jackman, Commission on the Future of Health Care in Canada, *The Implications of Section 7 of the Charter for Health Care Spending in Canada, Discussion Paper No. 31* (Ottawa: Health Canada, 2002) at 13 (arguing that section 7 of the *Charter* demands, *inter alia*, that policy and regulatory decision-making regarding allocation of health care resources must be made with adequate involvement of those whose fundamental interest are affected, and with particular attention to those lacking in resources and influence).

<sup>47</sup> [2001] OJ No 5057 (Sup Ct).

<sup>48</sup> *Ibid* at para 106.

<sup>49</sup> *Ibid* at para 34.

<sup>50</sup> See for example Jackman, “Health and Equality”, above note 25 at 111.

<sup>51</sup> *Ibid* at 110.

who are also more likely to be poor.<sup>52</sup> One solution to this problem is to urge, as Jackman and others rightfully have, a return to a meaningful application of substantive equality standards in judicial interpretations in section 15 analyses.<sup>53</sup> Another way to address the delisting process and its failures is to ensure that the groups most affected by delisting decisions are better represented, account for, and responded to. As suggested below, the seeds for such a legislative context are emerging in relation to health resource distribution in Canada.

## 2) International-level monitoring of health care allocation

Distributional features of Canada's healthcare system have received little mention in international-level human rights monitoring. Non-governmental organizations (NGOs) have certainly raised concerns about coverage in their submissions to the Committee on Economic, Social and Cultural Rights (CESCR).<sup>54</sup> One NGO shadow report has noted that the exclusion of prescription drugs, dental, and vision benefits from coverage under the public plan and provincial de-listing of hospital and physician services, together, make health services unaffordable for those who lack the means to pay.<sup>55</sup> Another has argued that the increasing reliance on private insurance and the lack of coverage of prescription drugs and physiotherapy has a disproportionate impact on First Nations people and people with disabilities.<sup>56</sup> Another report has expressed concerns about increasingly long

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<sup>52</sup> Council of Canadians with Disabilities, *Disabling Poverty and Enabling Citizenship: Understanding the Poverty and Exclusion of Canadians with Disabilities* (June 2010), online: CCD [www.ccdonline.ca](http://www.ccdonline.ca).

<sup>53</sup> Jackman, "Health and Equality", above note 25 at 132; Daphne Gilbert & Diana Majury, "Critical Comparisons: The Supreme Court of Canada *Dooms s. 15*" (2006) Windsor YB Access Just 111.

<sup>54</sup> See The Canadian Council for Refugees, the Canadian Council for Churches & The Inter-Church Committee for Refugees, *Draft Statement to the UN Committee on Economic, Social and Cultural Rights* (1998), online: Equality Rights [www.equalityrights.org](http://www.equalityrights.org) (the report notes "severe cutbacks" in health care for Canadians or permanent residents).

<sup>55</sup> See African Canadian Legal Clinic, *The Hidden Side of Paradise: Violations of the Economic and Social Rights of African Canadians*, Submission to the United Nations Committee on Economic, Social and Cultural Rights on the Occasion of the Review of Canada's Fourth and Fifth Periodic Reports Under the International Covenant on Economic, Social and Cultural Rights (May 2006) at 23, online: OHCHR [www2.ohchr.org](http://www2.ohchr.org).

<sup>56</sup> Kairos: Canadian Ecumenical Justice Initiatives, *Report on Cross-Canadian Citizen Dialogues on Social, Economic and Cultural Rights*, Submission to the United Nations Committee on Economic, Social and Cultural Rights 36th session (May 2006) at 16, online: CURA [www.socialrightscura.ca](http://www.socialrightscura.ca).

waitlists in the public system.<sup>57</sup> These distributional features have also been well documented in Canadian scholarship. Lahey, for example, has pointed out that Canada's health care system is primarily designed to meet the acute health care needs of otherwise healthy Canadians,<sup>58</sup> rather than the mental healthcare needs, home care needs, and pharmaceutical needs that are more prevalent among those who may be more politically, socially, or economically marginalized.

The CESCR, however, has yet to take up these concerns in any depth. In its 1993 Concluding Observations, the CESCR praised Canada's high standard of healthcare, as well as accountability created by the *Canada Health Act*.<sup>59</sup> In 1998, it recommended in general terms that "federal and provincial agreements . . . be adjusted so as to ensure, in whatever ways are appropriate, that services such as mental health care [and] home care . . . are available."<sup>60</sup> In 2006, the Committee expressed general concerns about health outcomes and access barriers faced by Aboriginal people, African Canadians, and homeless girls,<sup>61</sup> but had nothing but praise (however brief in length) for Canada's healthcare system as a whole.<sup>62</sup>

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<sup>57</sup> The St James Town LEAD Project (Local Empowerment and Access to Democracy & Residents of St. James Town), *Community Report on Economic Social and Cultural Human Rights in St. James Town, Toronto*, Draft UN Report for Residents/Community Review (2007) at 9, 11, 14, online: OHCHR [www2.ohchr.org](http://www2.ohchr.org).

<sup>58</sup> William Lahey, "Medicare and the Law: Contours of an Evolving Relationship" in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds, *Canadian Health Law and Policy*, 4th ed (Markham, ON: LexisNexis 2011) 1 at 79-80.

<sup>59</sup> United Nations Committee on Economic, Social and Cultural Rights, *Consideration of Reports Submitted by States Parties Under Articles 16 and 17 of the Covenant: Concluding Observations of the Committee on Economic, Social and Cultural Rights: Canada*, UNCESCROR, 1993, Supp No 3, UN Doc E/C.12/1993/5 at para 19.

<sup>60</sup> United Nations Committee on Economic, Social and Cultural Rights, *Consideration of Reports Submitted by States Parties Under Articles 16 and 17 of the Covenant: Concluding Observations of the Committee on Economic, Social and Cultural Rights: Canada*, UNCESCROR, 19th Sess, Supp No 2, UN Doc E/C.12/1/Add.31, (1998) at para 42.

<sup>61</sup> United Nations Committee on Economic, Social and Cultural Rights, *Consideration of Reports Submitted by States Parties Under Articles 16 and 17 of the Covenant: Concluding Observations of the Committee on Economic, Social and Cultural Rights: Canada*, UNCESCROR, 36th Sess, Supp No 2, UN Doc E/C.12/CAN/CO/4 & E/C.12/CAN/CO/5, (2006) at paras 15 & 57.

<sup>62</sup> *Ibid* at para 8 ("[t]he Committee notes with satisfaction the numerous health programmes conducted by the State Party, such as the 10-year Plan to Strengthen Health Care and the launch of the Public Health Agency").

The CESCR's relative silence on the growing inequities in health resource distribution in Canada may result from a number of factors. At a time when federal actors were abandoning their role in steering social welfare policies via conditional funding to the provinces, which were in turn slashing programs, the CESCR might have wisely chosen to focus its normative energies elsewhere.<sup>63</sup> Other obstacles to the CESCR addressing human rights dimensions of health resource distribution may relate to the theoretical quandaries pertaining to the right to health. One such obstacle is the unwieldiness of the principle of non-retrogression, particularly in the context of a relatively well-developed, single-payer health care system like Canada's. The concept of non-retrogression, which represents an effort to concretize the duty of progressive realization, has been variously defined<sup>64</sup> and criticized as an "extremely crude and unsatisfactory yardstick"<sup>65</sup> for measuring compliance with progressive realization. The principle notably fails to address what it means to move backward and obscures the need for old strategies to be abandoned and new strategies to be adopted in light of changing socio-economic circumstances.<sup>66</sup> In the case of health care in a well-developed country like Canada, retrogression and progression cannot easily be

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<sup>63</sup> See Shelagh Day & Gwen Brodsky, *Women and the Canada Social Transfer: Securing the Social Union* (Ottawa: Status of Women Canada, 2007) (for an account of the massive social welfare retrenchment that began in the 1990s).

<sup>64</sup> The principle is rarely carefully explored, and has been defined in numerous ways. See United Nations Committee on Economic, Social and Cultural Rights, *General Comment 3: The Nature of States Parties Obligations (art. 2, para. 1 of the Covenant)*, UNCESCROR, 5th Sess, UN Doc E/1991/23, (1990), at para 9 [*General Comment 3*] (suggests that it imposes a strong justificatory burden on states that would take any "deliberately retrogressive measures"); Maastricht Guidelines on Violations of Economic, Social and Cultural Rights (1998) 20:3 Hum Rts Q 691 at para 14(e) (going somewhat further and declaring it a violation for states to "adopt any deliberately retrogressive measure that reduces the extent to which any right is guaranteed"); Siddiqur Osmani, "Globalization and the Human Rights Approach to Development" in Bård A Andreassen & Stephen P Marks, eds, *Development as a Human Right* (Cambridge, MA: Harvard University Press, 2007) 265 at 278 (Osmani understands the principle to mean that "nobody should be allowed to suffer an absolute decline in the enjoyment of any right at any time" and that the principle "does not permit the level of enjoyment of any right to decline in comparison with the past").

<sup>65</sup> Mary Dowell-Jones, *Contextualising the International Covenant on Economic, Social and Cultural Rights: Assessing the Economic Deficit* (Leiden, The Netherlands: Nijhoff Publishers, 2004).

<sup>66</sup> *Ibid* at 52-4.

disentangled.<sup>67</sup> Indeed, critics of health care governance in Canada have complained that entrenched interests have blocked the abandonment of costly, antiquated treatments in favor of more cost-efficient ones.<sup>68</sup>

In addition, the continued influence of early “minimum core content” conceptions of economic, social, and cultural rights may suggest, spuriously, that when it comes to distributional questions, the right to health has greater application in developing countries or countries with very rudimentary health care infrastructure.<sup>69</sup> In its early work, the CESCR, reflecting prevailing academic views at the time,<sup>70</sup> sought to cabin and clarify obligations in the ICESCR not only through the principle of non-retrogression, but also through a concept of minimum core obligation linked primarily to subsistence-level needs.<sup>71</sup> Some theorists have doubted that anyone can properly define basic survival level needs, or that human dignity should be situated primarily at the level of what it takes to survive.<sup>72</sup> Others have suggested a more flexible minimum core that would place different obligations on countries of different

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<sup>67</sup> See for example Gunilla Backman et al, “Health Systems and the Right to Health: an Assessment of 194 Countries” (2008) 372:9655 *The Lancet* 2047 at 2049 (suggesting that the right to health is violated by an absolute lack of mental health facilities and asserting, without reference to a standard, that few countries devote adequate resources to mental health).

<sup>68</sup> Flood, Tuohy & Stabile, *Just Medicare*, above note 9. See also Lauchlan T Munro, “The Human-Rights Based Approach to Programming- A contradiction in Terms?” (Paper delivered at Conference on Winners and Losers from Rights-Based Approaches to Development, University of Manchester, England, 21-22 February 2005), online: School of Environment and Development [www.sed.man.ac.uk](http://www.sed.man.ac.uk) (Munro called non-retrogression a profoundly conservative concept for this reason).

<sup>69</sup> See for example Matthew Craven, *The International Covenant on Economic, Social, and Cultural Rights: A Perspective on its Development* (Oxford: Clarendon Press, 1998) at 143-44.

<sup>70</sup> See Karin Lehmann, “In Defense of the Constitutional Court: Litigating Economic and Social Rights and the Myth of the Minimum Core” (2006) 22 *Am U Int’l L Rev* 163 at 180. See also Young, above note 3 at 172 (noting that “most human rights scholars are minimum core campaigners”).

<sup>71</sup> See *General Comment No. 3*, above note 64 at para 10 (“[t]he Committee is of the view that a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon each State party. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant”).

<sup>72</sup> See Young, above note 3 at 130 & 131.

levels of development.<sup>73</sup> In addition, the CESCR's concept of the minimum core has evolved to include largely procedural obligations, alongside a substantive mainly survival-level minimum.<sup>74</sup> Nonetheless, the idea that the primary role of economic, social and cultural rights is to protect against the most severe cases of material deprivation has retained a persistent influence.<sup>75</sup> Whether the concept of minimum core, the difficulties of progressive realization, or political factors are to blame, the fact remains that while developing countries have attracted significant international human rights scrutiny in relation to the right to health, the human rights dimensions of policies in developed countries have received less attention.

### **C) An emphasis on processes for ensuring accountable policy**

Recently, however, strategies, methodologies, and rhetoric employed to identify and remedy exclusions of marginalized groups and individuals from social and state institutions have shifted. Traditional methodologies seek to identify explicit state violations of fixed rules against individual rights claimants. These have not been abandoned. However, as Bruce Porter describes in Chapter 1, a recent dynamism has emerged around new tools geared towards enhancing people's (especially marginalized people's) input

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<sup>73</sup> See *ibid* at 114 citing Asbjørn Eide, "Economic, Social and Cultural Rights as Human Rights" in Asbjørn Eide, Catarina Krause and Allen Rosas eds, *Economic, Social and Cultural Rights: A Textbook* (Dordrecht: Martinus Nijhoff Publishers, 2001) 27 and Craig Scott and Philip Alston, "Adjudicating Constitutional Priorities in a Transnational Context: A Comment on Soobramoney's Legacy and Grootboom's Promise" (2000) 16:2 SAJHR 206 at 250 (Young cites these authors who argue for and against a core content that would vary depending on resource availability. These authors indicate that countries with more resources have a higher level of minimum core obligation). See also Fons Coomans, "In Search of the Core Content of the Right to Education" in Danie Brand & Sage Russell, eds, *Exploring the Core Content of Economic and Social Rights: South African and International Perspectives* (Pretoria: Protea Book House, 2002) at 159 (the author suggests that a country-specific concept of the minimum core would undermine the universality of human rights).

<sup>74</sup> See *General Comment No. 14*, above note 7.

<sup>75</sup> See for example David Bilchitz, *Poverty and Fundamental Rights: The Justification and Enforcement of Soci-Economic Rights* (Oxford: Oxford University Press, 2007) at 179-80. Bilchitz prefers a universal survival-based definition of the minimum core). See also Young, above note 3 at 128-29, citing Henry Shue, *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy* (Princeton, NJ: Princeton University Press, 1996) at 19 (discussing how the focus on survival-level need helps bridge the divide between the better-established CPRs and ESCRs through a focus on the right to life and on the necessity of meeting basic needs if other rights are to be meaningfully enjoyed).

into policies that affect human rights, broadly understood.<sup>76</sup> Rights, therefore, become more concerned with ensuring—beyond the basic democratic processes and beyond international-level monitoring—transparency, accountability, and stakeholder participation in policies affecting human rights.

These newer interventions, advanced by human rights scholars and reflected in international institutions emphasize the need to address, rather than avoid, the problems of progressive realization and gaps in information. They do so by requiring states to identify and attend to obstacles to assessing progressive realization within their states as part of their international human rights obligations.<sup>77</sup> This approach has been described as a move beyond substantive monitoring of human rights fulfillment within states, to include, in addition, an appraisal of how well states monitor and account for their own

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<sup>76</sup> See Bruce Porter & Martha Jackman, Chapter 1; *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt*, UNGAOR, 4<sup>th</sup> Sess, UN Doc A/HRC/4/28, (January 2007), at para 26 & 87 [*Report of the Special Rapporteur, 2007*] (stating that “traditional” human rights tools like “naming and shaming, letter writing campaigns, test cases, sloganizing and so on” may have “served the human rights community well” for a time, but, recognizing the breadth of areas that affect the right to health, the need for the right to be operationalized through all of those areas, and recognizing the potential fluidity that lies beneath a concept like progressive realization, recommending “additional methods, techniques, and skills” including benchmarks, indicators, and impact assessments). See also Jonathan Klaaren, “A Second Look at the South African Human Rights Commission, Access to Information, and the Promotion of Socioeconomic Rights” (2005) 27:2 Hum Rts Q 539 (suggesting a national model of socioeconomic rights protection based on participation, transparency, and a constitutional right of access to information).

<sup>77</sup> See AnnJanette Rosga & Margaret Satterthwaite, “The Trust Indicators: Measuring Human Rights” (2008) 27:2 Berkeley J Int’l L 253 at 275 [Rosga & Satterthwaite]. See also *Report of the Special Rapporteur, 2007*, above note 76 at para 87 (“[w]ithout accountability, a State could use progressive realization and the scarcity of resources as an excuse to do virtually nothing - or to respond to whichever interest group has the loudest voice. Independent, effective and accessible mechanisms of accountability compel a State to explain what it is doing and why and how it is moving, as expeditiously and effectively as possible, towards the realization of the right to health for all”); *General Comment No. 14*, above note 7 at para 43(f) (requiring that states, as part of their minimum core obligations, set up and implement a national health plan; devise it using “participatory and transparent processes;” include methods such as indicators and benchmarks for measuring progress. It also requires that the content of the plan and the processes by which it is created “give particular attention to all vulnerable or marginalized groups”); Young, above note 3 at 116-18 (suggesting that theorists of economic and social rights should move away from substantive definition of the content of core rights and obligations and towards “concepts that facilitate rights’ content, operating as law,” including benchmarks, indicators, participatory processes, and justification requirements).

human rights fulfillment. This has been termed “monitoring-of-monitoring”<sup>78</sup> or “managing accountability.”<sup>79</sup> According to these approaches, states are expected to self-monitor using tools and processes which are themselves grounded in human rights principles and which themselves aim to render rights meaningful even when the rights’ substantive content might vary over time and context.

Procedurally-grounded human rights measures—such as human rights indicators, benchmarks, and impact assessments—are being developed so as to enhance somewhat less substantive human rights principles like accountability, transparency, non-discrimination, democratic participation, and individual self-determination.<sup>80</sup> They do not purport to give conclusive answers to questions about how priorities should be set among competing objectives.<sup>81</sup> Rather, in addition to being valued norms in themselves, these principles are expected to drive progressive realization<sup>82</sup> by seeking to ensure that decisions about priority setting are reasonable, transparent, informed by evidence, and take into account the needs of the most marginalized as

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<sup>78</sup> Rosga & Satterthwaite, *ibid* at 259.

<sup>79</sup> Tara Melish, “Maximum Feasible Participation of the Poor: New Governance, New Accountability, and a 21st Century War on the Sources of Poverty” (2010) 13:1 Yale Human Rts & Dev LJ 1 at 75 [Melish].

<sup>80</sup> See Joseph Raz, “Human Rights in the Emerging World Order” (2010) 1 Transnat’l Legal Theory 31 at 47 (describing a threefold role of human rights in the post-Cold War period as: “first . . . expressing the worth of all human beings; second . . . placing on the agenda concerns other than those of inter-governmental relations or big business profit; and third . . . empowering individuals and voluntary associations in creating an additional channel for exerting influence and affecting the international order,” while expressing concerns about institutional capacity and legitimacy of international institutions for enforcement of rights to health and education). See also Brigitte I Hamm, “A Human Rights Approach to Development” (2001) 23:4 Hum Rts Q 1005 at 1019-23; Mac Darrow & Amparo Thomas, “Power, Capture and Conflict: A Call for Human Rights Accountability in Development Cooperation” (2005) 27:2 Hum Rts Q 471 at 493 (noting that there can be normative or instrumental rationales for adopting human rights-based approaches to programming and development, but that instrumental conceptions “seem to be the most compelling;” stating also that “this rationale harnesses human rights ideas and energies in order to reach the excluded, or reinforces participatory approaches to situation assessment, empowering people as actors for their own development, strengthening institutions of governance and accountability, and so on”).

<sup>81</sup> *Report of the Special Rapporteur, 2007*, above note 76 at paras 26, 29, 87.

<sup>82</sup> *Ibid* at para 27. See also Alicia Ely Yamin, “Defining Questions: Situating Issues of Power in the Formulation of a Right to Health under International Law” (1996) 18:2 Hum Rts Q 398 at 407 [Yamin, “Defining Questions”] (suggesting that the “distinction between instrumental and normative value of defining health as a human right collapses” when rights are understood to advance empowerment as both as goal and strategy).

understood by the most marginalized.<sup>83</sup> The growing popularity of these tools, which are applicable to economic, social and cultural rights (ESCR) and also to civil and political rights (CPR),<sup>84</sup> suggests that human rights are relied upon increasingly for their values-driven, governance-enhancing function over any fixed, detailed substantive normative content they might prescribe.<sup>85</sup> That is, deliberation-enhancing, accountability-oriented processes are used to create spaces of contestation—and to suggest values that might inform that contestation.

For example, the work of the former UN Special Rapporteur on the Right to Health, Paul Hunt, has come to place heavy emphasis on right-to-health indicators.<sup>86</sup> These indicators reflect processes, structures and

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<sup>83</sup> See Paul Hunt & Gillian MacNaughton, *Impact Assessments, Poverty and Human Rights: A Case Study Using the Right to the Highest Attainable Standard of Health* (31 May 2006) at 30 [Hunt & MacNaughton], citing *General Comment No. 14*, above note 7 at para. 11, online: WHO [www.who.int](http://www.who.int) (noting, for example, that "a further important aspect of the right to health "is the participation of the population in all health-related decision-making at the community, national, and international levels." Participation implicates, among other factors, the rights to seek and impart health-related information, the right to express views freely, and the right to basic health education, as well as transparency in policymaking processes. Full participation on a non-discriminatory basis also requires special attention to sharing information with and seeking the views of women and men, as well as the views of vulnerable and marginalized people"). See also Paul Hunt & Gunilla Backman, "Health Systems and the Right to the Highest Attainable Standard of Health" (2008) 10:1 *Health & Hum Rts* 81 at 83 [Hunt & Backman].

<sup>84</sup> Rosga & Satterthwaite, above note 77 at 266, citing Charles Humana, *World Human Rights Guide* (London: Hutchison, 1983); Charles Humana, *World Human Rights Guide* (London: Hodder & Stoughton, 1986). (explaining how social scientists interested in applying statistical tools to civil and political rights began using indicators to assess states' overall human rights performance. Humana assigns percentage ratings to countries based on scores concerning forty CPRs, and ranking them "good, fair, poor or bad").

<sup>85</sup> Scott Cummings & Louise Trubek, "Globalizing Public Interest Law" (2008) 13 *UCLA J Int'l L and Foreign Aff* 1 (describing a "rule of law" movement relying on the language of human rights to "temper excesses of open markets with appropriate regulation and democratic rights").

<sup>86</sup> See *Report of the Special Rapporteur on the right to the highest attainable standard of health to the Commissioner on Human Rights- Paul Hunt*, UNESCOR, 62nd Sess, UN Doc E/CN.4/2006/48 (2006) (a recent effort to operationalize this model to evaluate the health systems of the full range of states sets out some 72 indicators. Many of these can be understood as outcome indicators, such as infant mortality rates and life expectancy, but many are better understood as requirements for domestic monitoring designed to leverage local political processes: the existence of a health plan, whether there is legal protection for participation of the marginalized within that health plan, and even transparency in national financing). See Backman et al, above note 67 at 2057-58.

institutions linked to health, in addition to health itself. For example, *General Comment No. 14*<sup>87</sup> requires that indicators measure whether states have adopted a national public health strategy that includes the right to health, whether the plan is formulated and monitored through the participation of “the most vulnerable and disadvantaged” individuals and groups, and whether there are effective internal monitoring and accountability mechanisms.<sup>88</sup> Emphasis is placed on states’ duties to generate data in relation to health indicators that is disaggregated to reflect contextual vulnerability and discrimination<sup>89</sup> and on states’ duties to monitor their own progress internally through indicator-based benchmarking.<sup>90</sup> The depth of monitoring-of-monitoring is vividly reflected in the fact that right-to-health indicators even measure the extent to which states undertake health or right-to-health impact assessments prior to adopting national health plans. The result is that indicators move from being a tool for Committee-level assessment of states’ progressive realization to driving internal processes likely to improve right to health outcomes by bringing to light discriminatory, arbitrary, or ineffective policies.<sup>91</sup> Indicator-based monitoring is relied upon for opening up spaces for civil society participation in generating systemic human rights-based reform

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<sup>87</sup> *General Comment No. 14*, above note 7 at para 43.

<sup>88</sup> *Ibid* at para 49(c).

<sup>89</sup> *Ibid* at para 49(b).

<sup>90</sup> *Ibid* at paras 35 & 58. See especially *ibid* at para 34 (emphasizes the key role indicators play in driving internal accountability and participation: “... [i]ndicators and benchmarks fulfill two important functions that underpin much of the discussion in this chapter. *First*, they can help the State to monitor its progress over time, enabling the authorities to recognize when policy adjustments are required. *Second*, they can help to hold the State to account in relation to the discharge of its responsibilities arising from the right to health, although deteriorating indicators do not necessarily mean that the State is in breach of its international right to health obligations, an important point which is discussed further below. Of course, indicators also have other important roles. For example, by highlighting issues such as disaggregation, participation and accountability, indicators can enhance the effectiveness of policies and programmes.” (emphasis in original).

<sup>91</sup> See also Hunt & MacNaughton, above note 83 at 57 (defining the right to health as the “right to enjoy a variety of goods, facilities and services that are necessary to realize the highest attainable standard of health”).

at national and subnational levels.<sup>92</sup> Hunt and MacNaughton, although they admit the novelty of the concept,<sup>93</sup> argue that human rights impact assessment is “highly recommended, *if not required*, [for states] to comply with [their] international human rights obligations to progressively realize human rights.”<sup>94</sup>

This shift in emphasis towards participation and accountability as a driver of progressive realization is not limited to the UN institutional actors or those who explicitly adopt their frameworks. For example, as Vincent Greason notes in Chapter 9, there has been increasing reliance on measurement rather than values of social solidarity in anti-poverty policies in Canada.<sup>95</sup>

Greason remains profoundly skeptical of indicators, viewing them as open to manipulation by governments seeking to set the terms of progress so that they can claim to have achieved it, all the while distracting from neoliberal moves away from redistribution.<sup>96</sup> Other human rights scholars and right to health scholars in particular, have expressed similar skepticism.<sup>97</sup> Some, however, have elaborated upon and refined how indicators can contribute to a human right to health understood in terms of locating responsibility and opening spaces for meaningful participation in determining health-affecting state policies through monitoring processes.

Alicia Ely Yamin, for example, emphasizes empowerment as an underlying theme in human rights and suggests re-framing the right to health as “the highest attainable standard of *control over* health.”<sup>98</sup> She notes that poor health is “the product not only of human beings’ incomplete domination

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<sup>92</sup> See for example Alicia Ely Yamin, “The Future in the Mirror: Incorporating Strategies for the Defense and Promotion of Economic, Social and Cultural Rights into the Mainstream Human Rights Agenda” (2005) 27:4 Hum Rts Q 1200 at 1207 and 1212 [Yamin, “Future in the Mirror”] (arguing that human rights organizations should move beyond identifying individual-level violations and instead collaborate with other disciplines like public health to use indicators, such as rates of access to emergency obstetric care, in order to advocate in relation to structural and institutional factors in human rights and to create a “starting place for defining appropriate measures for governments to take towards progressive realization”).

<sup>93</sup> Hunt & MacNaughton, above note 83 at 9.

<sup>94</sup> *Ibid* at 7 [emphasis added].

<sup>95</sup> See Vincent Greason, Chapter 9.

<sup>96</sup> *Ibid*.

<sup>97</sup> See for example Sally Engle Merry, “Measuring the World: Indicators, Human Rights, and Global Governance” (2011) 52:3 Current Anthropology at S83.

<sup>98</sup> Yamin, “Defining Questions,” above note 82 at 400 [emphasis in the original].

of nature, but of the domination of some people by others.”<sup>99</sup> The central task of human rights and right to health activists is redefined as an exploratory one: “to discern the societal relations, combinations, and alignments of power that both produce and distribute disease . . . .”<sup>100</sup> Yamin would seek to shift the dialogue in the right to health to “reveal the human role in constructing health and illness.”<sup>101</sup> In doing so, she would reject (perhaps provisionally) any normative account of an ideal health care regime, and focus instead on fleshing out the meaning of empowerment in context and through collaboration with affected communities themselves.<sup>102</sup> In 1996, Yamin was skeptical of indicators as a process for achieving empowerment as she worried they might render human rights monitoring too technocratic.<sup>103</sup> By 2005, Yamin advocated that progressive realization could be driven by indicators, so long as those indicators remain contestable, not overly technocratic in that they include the qualitative, and defined through the collaboration of human rights NGOs with other stakeholders including public health actors.<sup>104</sup>

AnnJanette Rosga and Margaret Satterthwaite likewise respond to concerns over the risks of indicators by emphasizing the role of meaningful participation in creating a contestable set of indicators. They suggest that “indicators must be created that will measure the participation of the populace in decisions affecting both institutional design and policy priorities in the field of human rights” and that “participation should . . . extend to the process of designing and implementing indicators themselves.”<sup>105</sup>

This new accountability-centered focus, whereby public goods are scrutinized not (primarily) for their substantive distribution, but for whether processes for distribution comply with foundational human rights principles, does hold some theoretical promise for human rights-based assessments of health systems in Canada. By recognizing that all rights have components

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<sup>99</sup> *Ibid* at 402.

<sup>100</sup> *Ibid*.

<sup>101</sup> *Ibid* at 412.

<sup>102</sup> *Ibid* at 436 & 438.

<sup>103</sup> *Ibid* at 410-11 (expressing the concern that indicators will render health status “an objective, quantitative quality . . . one more output to be produced . . . to be measured according to standardized morbidity and mortality indicators . . . [turning] human beings (and their behaviors) into one more input and thus the targets of incentive changes and objects of surveillance”).

<sup>104</sup> Yamin, “Future in the Mirror,” above note 92 at 1210 (“[i]f human rights groups are willing to work with other disciplines . . . [indicators] can form the basis for the standard-setting work the human rights movement has successfully engaged in for years with respect to many civil and political rights issues, including prison conditions”).

<sup>105</sup> Rosga & Satterthwaite, above note 77 at 313-14.

whose contents are in evolution and which can be better enforced through participation, accountability, and monitoring, it diminishes the argument that CPRs and ESCRs are of fundamentally different natures, with ESCRs occupying the lower rung.<sup>106</sup> Likewise, where states' duties to self-monitor, disaggregate data, benchmark, and open up participation in human rights related policymaking occupy a more central place among their human rights obligations, the differences between "violations" and "minimum core" approaches on the one hand and progressive realization on the other, diminish.<sup>107</sup> Free of the need for universal substantive normativity, "immediately enforceable" ESCRs need not be restricted to the level of basic survival and can have greater resonance in a well-developed health care system. Unjustifiable choices rooted in power, ignorance, or stereotype—what some might consider systemic discrimination, which traditional approaches have failed to address—cannot hide as easily behind privatized and disaggregated lines of responsibility and authority when they are brought into the public sphere through accountability and participation requirements. Concerns about transparency, accountability, and substantive distribution in Canadian healthcare—well-voiced in the political sphere—may be structured in concrete human rights terms.

Although the new emphasis on processes in human rights implementation is relatively recent, its set of core themes is not. A number of authors have noted common intellectual underpinnings and features of the new conceptions of accountability and responsibility in human rights and new ideas about governance in the public sector (including health policy).<sup>108</sup> That is, the driving themes here—enhancing democratic governance through flexible norm-setting that responds to community-level needs, reliance on transparent, deliberative processes, evidence-based decision making, and citizen participation—are closely paralleled in public (including health) policy literature in Canada and internationally.<sup>109</sup> The emphasis on these core themes has increased as resource constraints have put pressure on the Canadian health care system and raised concerns about accountability in the scope and distribution of publicly-funded services. The next section will examine the evolution of health governance in Canada along such lines, with a view to exploring how Canada might respond to the demands of the procedural dimensions of the human rights to health and to expose contextual challenges to the procedural project in the human right to health.

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<sup>106</sup> See also Yamin, "Defining Questions," above note 82.

<sup>107</sup> See Young, above note 3 at 166; Rosga & Satterthwaite, above note 77 at 265.

<sup>108</sup> Lisa Alexander, "Stakeholder Participation in New Governance: Lessons From Chicago's Public Housing Reform Experiment" (2009) 16:1 *Geo J on Poverty L & Pol'y* 117; Melish, above note 79.

<sup>109</sup> See Norman Daniels & James Sabin, "The Ethics of Accountability in Managed Care Reform" (1998) 17:5 *Health Affairs* 50.

#### **D) Participatory governance in Canadian health care priority-setting**

Government did not always play an active role in determining the distribution of healthcare in Canada. In the early days of public insurance, government simply underwrote the hospital and physician services that already existed and distribution was effectively left to the clinical judgment of individual physicians. From Medicare's inception in the 1960s until significant cuts in the 1990s, costs were kept in check largely without resort to restricting services available under the public plan.

The passage of time, however, brought new challenges and conceptions around health, medical care, and insurance that fundamentally tested the conception of Medicare rooted in the 1960s. New technologies made costlier interventions possible. The importance of health interventions outside of covered hospital and physician services became clearer. Governments experimented with hospital restructuring, and delisting of services as ways of controlling escalating costs.<sup>110</sup> However, the major change in management of health care distribution came through regionalization.

In the late 1980s and early 1990s, each province established a task force or commission of inquiry to deal with health care costs in times of economic restraint.<sup>111</sup> All reflected a similar set of general goals. Many were about efficiency: better health outcomes with less overall spending. Others addressed broader political concerns like increasing accountability of decision-makers and enhancing citizen participation. Suggested directions for achieving those goals included a shift from institutionally-based to community-based care, a focus on a broader range of health determinants beyond the health care delivery system, making room for the representation of a variety of interests in the health field in health policy planning, and the integration of services across the continuum of care.<sup>112</sup> Regionalization of health care was the favored structural approach for achieving these reforms

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<sup>110</sup> Carolyn Hughes Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain, and Canada* (New York: Oxford University Press, 1999) at 180 [Tuohy, *Accidental Logics*].

<sup>111</sup> For a summary, see Sharmila L Mhatre and Raisa B Deber, "From Equal Access to Health Care to Equitable Access to Health: A Review of Canadian Provincial Health Commissions and Reports" (1992) 22:4 *Int'l J Health Services* 645; Gregory Marchildon, *Health Systems in Transition: Canada* (Toronto: University of Toronto Press, 2006) [Marchildon] (these sources provide a summary).

<sup>112</sup> Tuohy, *Accidental Logics*, above note 110 at 97.

and was adopted from the late 1980s through the 1990s in every province<sup>113</sup> except Ontario, which finally adopted a form of regionalization in the mid-2000s.<sup>114</sup>

Regionalization was expected to help in a number of ways. It was expected to allow resources to move more fluidly in response to local needs, as regions would be required to assess the health care needs of their populations and craft plans setting out how they anticipate meeting those needs.<sup>115</sup> It was envisioned that increased reporting of spending, projected and actual health outcomes, and wait times—as would be necessary for redistributing funding within regions—would result in more direct accountability to local citizens and make funding less conventionally politicized and less dominated by professional interests.<sup>116</sup> Other ostensible benefits included increased service quality and reliance on evidence-based practice, as well as increased spaces for public participation.<sup>117</sup> Less optimistically, regionalization can be understood as a way to contain discontent and conflict as service expectations seem increasingly to exceed what governments are prepared to pay for.<sup>118</sup>

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<sup>113</sup> Marchildon, above note 111 at 108-9 (there has since been some retreat from regionalization: Prince Edward Island, Canada's smallest province with a population of 140 000, eliminated regional boards in 2005. See Donald J Philippon & Jeffrey Braithwaite, "Health System Organization and Governance in Canada and Australia: A Comparison of Historical Developments, Recent Policy Changes and Future Implications" (2008) 4:1 *Healthcare Policy* 168 at 178 (in 2008, Alberta announced that it would create a single "super-region," but one that would maintain the consolidation of authority and the accountability requirements under the *Regional Health Authorities Act*); Tom McIntosh et al, "Population Health and Health Reform: Needs-Based Funding in Five Provinces" (2010) 4:1 *Can Pol Sci Rev* 42 at 48 [McIntosh et al].

<sup>114</sup> See Robert Bardner, *Local Health Integration Networks: Potential, Challenges and Policy Directions*, online: The Wellesley Institute <http://wellesleyinstitute.com> (for a description of the Ontario experience,). See also B Moloughney, *A Discussion Paper on Public Health, Local Health Integration Networks, and Regional Health Authorities*, online: OPHA [www.opha.on.ca](http://www.opha.on.ca) [Moloughney] (criticizing the Ontario regional structure for failing to include authority over public health, and for failing to eliminate hospital boards).

<sup>115</sup> Marchildon, above note 111 at 107; Colleen Flood, Duncan Sinclair & Joanne Erdman, above note 1 at 176.

<sup>116</sup> Steven Lewis & Denise Kouri, "Regionalization: Making Sense of the Canadian Experience" (2004) 5:1 *Healthcare Papers* 12 at 15-20 [Lewis & Kouri].

<sup>117</sup> See Jonathan Lomas, "Devolving Authority for Health Care in Canada's Provinces: 4 Emerging Issues and Prospects" (1997) 156 *Can Med Ass'n J* 817 at 819 [Lomas]; Flood, Sinclair & Erdman, above note 1; Lewis & Kouri, *ibid* at 16.

<sup>118</sup> Lomas, *ibid* at 818.

The most significant accountability-related achievement resulting from regionalization is the improved transparency achieved through bottom-up reporting mechanisms. Working within broad provincially-set parameters,<sup>119</sup> Regional Health Authorities (RHAs) must typically develop and publicize a regional plan setting out how they will meet statutory obligations to provide for the health needs of the population.<sup>120</sup> As for reporting requirements themselves, each RHA is statutorily required to report publicly on the extent to which its plans are met through some combination of financial reports, audited statements, and, most novel in this context, indicators of the health status of the population and the efficacy of the RHA

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<sup>119</sup> See for example *Regional Health Authorities Act*, SNB 2002, c R-5.05, s 6(1) [*New Brunswick Regional Health Authorities Act*] (which sets out guidelines for the development of the provincial health plan); *Regional Health Services Act*, SS 2002, c R-8.2, s 4 [*Saskatchewan Regional Health Services Act*] (which affirmed that the minister (i.e., the provincial government) is responsible for overall strategic direction, including, *inter alia*, the establishment of goals, objectives, performance measures and targets, and development of methodologies for resource allocation).

<sup>120</sup> See for example *New Brunswick Regional Health Authorities Act*, *ibid* at s 32(1); *Health and Community Services Act*, SNL 1995, c. P-37.1, ss 16, 21(1) [*Newfoundland and Labrador Health and Community Services Act*]; *Regional Health Authorities Act*, CCSM c R34, ss 24(1), 34(3) [*Manitoba Regional Health Authorities Act*]; *Saskatchewan Regional Health Services Act*, *ibid*; *Regional Health Authorities Act*, RSA 2000, c R-10, s 9(1) [*Alberta Regional Health Authorities Act*]; *Health Authorities Act*, RSBC 1996, c 180, s 5 (1)(a) [*British Columbia Health Authorities Act*]; *Act Respecting Health Services and Social Services*, RSQ, c S-4.2 ss 346(1), 350, 385(1)-(3) [*Quebec Act Respecting Health*] (Quebec's legislation requires RHAs to set out multi-year strategic plans supplemented by an annual "management and accountability agreement" negotiated between the provincial government and the RHA. Statutory duties of RHAs vary from province to province. The *Quebec Act Respecting Health*, at section 340, lists RHA duties including allocating budgets, ensuring public participation, ensuring efficient distribution of resources, assessing the results of the implementation of its strategic plan, and carrying out any other mandate entrusted to it by the minister). *New Brunswick Regional Health Authorities Act*, *ibid* at s 30 (responsibilities of RHAs in the *New Brunswick Regional Health Authorities Act* are simpler: determining needs, setting priorities and allocating resources). See also *Health Authorities Act*, SNS 2000 c 6, s 19-20 [*Nova Scotia Health Authorities Act*].

basket of services.<sup>121</sup> In addition, most RHA legislation places a premium on the flexibility of objectives and modes of assessment<sup>122</sup> and RHAs increasingly negotiate the addition of accountability mechanisms through “performance agreements” with the provinces and incorporate these into their mandate beyond what is explicitly set out in statutes.<sup>123</sup> RHAs are also required to ensure the release of reports on progress towards achievement.<sup>124</sup> The combined result has been a massive shift towards the use of targets or benchmarks, followed by the collection of statistical indicators of population

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<sup>121</sup> The detail with which legislation prescribes the content of reports varies. See e.g. *Alberta Regional Health Authorities Act*, *ibid* at s 9 (4)(a), 14(2)(b) (in Alberta, for example, annual reports must contain audited financial information, senior management and board remuneration, and “other performance information required by regulation”); *Manitoba Regional Health Authorities Act*, *ibid* s 38(2) (Manitoba legislation specifies that annual reports shall contain, in addition to financial statements, the health services provided, their costs, and a “report respecting the health status of the population and the effectiveness of the health services provided or funded by the regional health authority”); *Nova Scotia Health Authorities Act*, *ibid* s 21(1)(c) (in Nova Scotia, the legislation is more open-ended: district health authorities are required to provide financial statement and “such information as is required by the Minister for the purpose of monitoring and evaluation of the quality, accessibility and comprehensiveness of health services”).

<sup>122</sup> *Saskatchewan Regional Health Services Act*, above note 119 at s 54(2); *British Columbia Health Authorities Act*, above note 120 at s 7(2); *Newfoundland and Labrador Health and Community Services Act*, above note 120 at s 24.

<sup>123</sup> See Mark Considine, “The End of the Line? Accountable Governance in the Age of Networks, Partnerships, and Joined-Up Services” (2002) 15:1 *Governance* 21 at 22 (performance agreements are becoming an increasingly common tool in the public sector for governments to set the course for agencies without micromanaging their work. These are most prominently used in British Columbia and Quebec, where they are becoming increasingly elaborate.). *Quebec’s Act Respecting Health*, *supra* note 111 at s 387.5 (this section explicitly requires the use of performance agreements and consequent reporting. Section 385.7 requires that the annual report measure results against the plan in the management and accountability agreement. In addition, legislation requires each RHA to report on the reliability of the data and the monitoring mechanisms. See also British Columbia Ministry of Health, online: Ministry of Health [www.health.gov.bc.ca](http://www.health.gov.bc.ca) (BC consolidates its RHA reports and publishes them on the Ministry of Health website).

<sup>124</sup> British Columbia Ministry of Health Services, *Report on Health Authority Performance Agreements 2002/2003* at 6, online: Ministry of Health [www.health.gov.bc.ca](http://www.health.gov.bc.ca) (the British Columbia Ministry of Health Services describes the purpose of reports pursuant to performance agreements as “an opportunity to compare the performance of health authorities relative to each other, Ministry expectations, and to provide the public with ongoing information on the impact of redesign on patient services”).

health, service usage, wait times, and other aspects of system effectiveness.<sup>125</sup> Flood and Archibald have described this new indicator based system as a “significant improvement on what provincial governments were historically prepared to divulge to citizens.”<sup>126</sup>

Nonetheless, regionalization has not fully lived up to its promise. The most oft-cited obstacle is the failure of most regions to situate full fiscal responsibility for all services within a given region.<sup>127</sup> A broad conception of the social determinants of health would suggest a very wide range of community services be included within a RHA’s budget.<sup>128</sup> However, both physician remuneration<sup>129</sup> and drug plans outside hospitals<sup>130</sup> have been left out of RHA budgets, undermining their capacity to redirect funding where participatory processes reveal that it is most needed. In Ontario, regional distribution has allegedly been captured by the interests of policy makers and private medical practitioners whose financial interests are at odds with the promotion of investment in “upstream” factors like social determinants of health.<sup>131</sup> In other words, curative approaches are being unjustifiably preferred, even where preventative approaches that address the social inequities and inequalities that drive poor health might result in better health outcomes. Capture and politicization may explain why, despite legislation demanding responsive planning, in most cases “this year’s plan is last year’s plan slightly twiggled to reflect updated information.”<sup>132</sup> Part of the problem may lie in the technical challenge of drawing up formulas for determining relative need that extend beyond age-and-gender-adjusted population

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<sup>125</sup> Colleen Flood & Tom Archibald, *Hamstrung and Hogtied: Cascading Constraints on Citizen Governors in Medicare* (2005), online: CPRN [www.cprn.org](http://www.cprn.org) [Flood & Archibald].

<sup>126</sup> *Ibid* at 25. See *Manitoba Regional Health Authorities Act*, above note 120 at s 38(2); *Quebec Act Respecting Health*, *supra* note 119 at s 346.

<sup>127</sup> Flood, Sinclair & Erdman, above note 1 at 193; Lomas, above note 117 at 823-24; Lewis and Kouri, above note 116 at 20-3; Moloughney, above note 114.

<sup>128</sup> See See Michael Marmot, "Social Determinants of Health Inequalities" (2005) 365 *The Lancet* 1099 (setting out the potential breadth of the concept of social determinants of health).

<sup>129</sup> Lewis & Kouri, above note 116 at 25.

<sup>130</sup> *Ibid* at 25.

<sup>131</sup> McIntosh et al, above note 113.

<sup>132</sup> Jeremiah Hurley, "Regionalization and the Allocation of Healthcare Resources to Meet Population Health Needs" (2004) 5:1 *Healthcare Papers* 34 at 36 [Hurley].

counts,<sup>133</sup> and the fear that such formulas might become so complex that they shut out stakeholder participation.<sup>134</sup> The difficulties associated with implementing needs-based funding also suggest that it may be impossible to depoliticize allocation decisions within regions.<sup>135</sup>

Instead, the goals of regionalization and rationalization might be better understood not as de-politicizing but modifying the political environment in which the decisions are made. Regionalization and needs-based assessment should not be understood to offer a technocratic solution to moving away from hospital and physician based care and towards prevention, health promotion, and other upstream investments, or to be the solution to the broader problem of spending wisely and fairly. Instead, their promise lies in setting the stage for more transparent allocation, and, much like the new emphasis in human rights approaches set out above, opening up new kinds of spaces for democratic accountability and participation beyond the ordinary political process. Understanding whether the ostensible shifts towards evidence-based distribution through regional consolidation have indeed opened up new spaces for determining the distribution of health care resources particularly for marginalized groups, requires an examination of the accountability frameworks that have accompanied the move towards regionalized governance. This presents a new challenge to social and economic rights advocates, monitors and judges: to attend to the ways in which transparent, accountable governance can reveal and provide space to address illegitimate exercises of power as part of the human rights project.

#### **E) Conclusion: New agendas in Human Rights Monitoring, Advocacy, and Scholarship**

In this paper I have argued that human rights actors might usefully take advantage of this shift towards participatory and accountable governance in both right-to-health and in health resource allocation. The move towards regionalization, accompanied as it has been by preoccupations over ensuring accountability, participation, and evidence-based policy, appears notably apt to incorporating new conceptions of human rights and the right to health, as described above. Like the human rights approaches, such an approach begins by recognizing the disproportionate emphasis on curative provisos over social and structural determinants of health. It seeks to dis-entrench structures that support an anachronistic reliance on curative models, and move away from arbitrary, inefficient, and ineffective allocation decisions by coordinating

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<sup>133</sup> See for example McIntosh et al, above note 113.

<sup>134</sup> Hurley, above note 132.

<sup>135</sup> *Ibid* (stating that in retrospect the optimism around needs-based funding coupled with regionalization was unfounded, and that this “perhaps should have been obvious when one reflects how difficult reallocation is within fully integrated, hierarchical organizations, much less a regional health authority with far more muted power”).

services<sup>136</sup> and the opening up of priority-setting mechanisms to flexible, transparent, accountable, and participatory local-level decision making. Participation is sought; transparency and accountability are, likewise, pursued through public planning and reporting. Through orchestration, including comparison of targets and means of achieving progress towards those targets, it might promote continual improvement by revealing progress over time.

At the same time, context is important. Canada's new institutions for managing health care distribution were not designed as, nor do they fully reflect a participation-oriented human rights-based approach to determining distribution of health care resources in Canada. Politically, these changes were motivated by concerns about service integration, cost containment, and communicating accountability to an increasingly dissatisfied public. The changes were also justified publicly with reference to their value for citizen engagement.<sup>137</sup> Unfortunately, in practice the programs are not primarily designed to ensure genuinely responsive, human rights oriented health care allocation decisions. Nonetheless, the ostensible reliance on participatory, transparent, accountable governance to ensure fair and reasonable allocation in both the right to health and in health governance offers new opportunities for advocacy, as well as new questions with which to struggle.

As to the judicial challenges noted above, the existence of such accountability and participation requirements might bolster traditional human rights claims. For example, had human rights-based obligations of participatory accountability guided the process for determining the de-listing of sex reassignment surgery in *Hogan*, the result might have been very different. The *Auton* court, for its part, might have been less fearful of examining the *bona fides* of the claim to services if the choice of which services to provide had been grounded in a more robust and transparent participatory accountability framework.

In terms of policy advocacy, human rights lend credence to the suggestion that if participation, transparency and accountability form the basis of more responsive decision-making, such governance should be extended to *all* health-affecting services.<sup>138</sup> There is, of course, a risk of overextending the scope of what health authorities are required to consider. This potential overextension is a key criticism of the human rights focus on social determinants of health. The more factors that go into reports, indicators, and benchmarks, the greater the risk that spaces opened up for democratic

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<sup>136</sup> Hunt & Backman, above note 83 at 47-8.

<sup>137</sup> Lomas, above note 117 (noting the empowerment rhetoric that came along with regionalization, but doubting whether community participation was ever necessary to the central vision of regionalization, and suggesting that empowerment was bound to take a backseat to cost-cutting goals).

<sup>138</sup> See Martha Jackman, "The Right to Participate in Health Care and Health Resource Allocation Decisions Under Section 7 of the Canadian Charter" (1995/1996) 4:2 Health L Rev 3.

participation will be too complex for stakeholders to navigate. In this particular context, however, this difficulty is largely outweighed by the concerns noted by those committed to a fair distribution of health resources based on need rather than ability to pay. They argue that the historic focus on funding hospital and physician services operates at the expense of social determinants—the social and political exclusion and inequality that drives poor health. Placing social determinants on a level, deliberative playing field may be the best way to ensure the process of identifying and ranking determinants (even as they remain potentially boundless) against traditional health services becomes possible in the context of ossified health care allocation structures.

Finally, given the increasing importance placed on participation and accountability at the international level, human rights monitors, scholars, and advocates should carefully monitor the practice of participatory governance in the Canadian health care context, with a view to evaluating whether, when, and how meaningful participation can be assured in these kinds of contexts. Human rights can provide important justification for insisting on real rather than ‘sham’ opportunities for participation. In practice, most RHA legislation in Canada provides only modestly for citizen involvement.<sup>139</sup> Processes themselves may not create room for meaningful participation, for example, when uni-directional flows of information (typically from professionals to citizens) have stood in place of real deliberative exchange,<sup>140</sup> or information presented was too technical or rushed through for participants to understand.<sup>141</sup> Moreover, there is little evidence that citizen deliberators are actually listened to.<sup>142</sup> A more troubling problem is addressing power differences among participants. Left unassisted, those with the fewest resources are likely to be least able to participate. Unstructured participation might result in certain citizen voices being disproportionately heard. Expensive autism treatment<sup>143</sup> may generate more support than inexpensive,

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<sup>139</sup> See Flood & Archibald, above note 125 at 23-5.

<sup>140</sup> Julia Abelson et al, "Deliberations about Deliberative Methods: Issues in the Design and Evaluation of Public Participation Processes" (2003) 57:2 Soc Sci & Med 239 at 246.

<sup>141</sup> *Ibid.*

<sup>142</sup> *Ibid* at 247.

<sup>143</sup> Eric Fombonne, "The Prevalence of Autism" (2003) 289:1 J Am Med Ass 87 at 89 ("... ironically, what has triggered substantial social policy changes in autism appears to have little connection with the state of the evidence. . . . [F]urther consideration should be given to how and to why the least evidence-based claims have achieved impressive changes in funding policy")

but equally effective needle-exchange programs.<sup>144</sup> At the same time, there is a risk that deliberative processes will become bare cost-benefit analyses along axes of measurement set and controlled by those in power.<sup>145</sup> Some health services, such as palliative care, may be important but resistant to measurement in terms of health outcomes, such as palliative care. Scholars and activists contending with the move towards human rights based governance processes will need to contend with these difficulties if the move towards justificatory, participatory processes persists.

It is always possible that the turn towards participatory processes in international law is a misguided one. Canada's experiences will help determine whether traditional methods of locating violations based on set substantive norms remains preferable. However, it is important to remember where we started. These approaches may provide novel avenues for addressing ossified, substantively discriminatory, and arguably, retrogressive distributions of health resources in Canada that have proved difficult to address adequately under traditional human rights scrutiny. In turning towards the procedural considerations, the right to health makes a modest step and a bold one. Modestly, it gives traction (without deciding) to concepts like "progressive realization" and the ultimately indeterminate "core obligations." More boldly, it locates the denial of the right to health squarely in the disenfranchisement and disempowerment of citizens from control over what affects their body. In doing so, the human right to health both delegitimizes professional and market capture and renews its own fundamental challenge of guaranteeing dignity-based self-realization.

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<sup>144</sup> Franklin Laufer, "Cost-effectiveness of syringe exchange as an HIV prevention strategy" (2001) 28:3 *Journal of Acquired Immune Deficiency Syndromes* 273 at 277.

<sup>145</sup> See Kevin Davis, Benedict Kingsbury & Sally Engle Merry, "Indicators as a Technology of Global Governance" (2012) 46:1 *Law & Soc Rev* 71.