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“Citizen Participation in Just Canadian Health Care”

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Good Morning. It is an honor to be with you. My thanks to the organizers of this conference for choosing this Symposium topic and to those who made our getting and being here so easy.

This morning I’ll speak about one aspect of a larger project I’m working on about the roles of local and other communities in just health care in the United States. I look to Canada, not just because my father’s family is from Canada or because the Canadian experience is interesting in its own right, both are true, but I study Canada also as an antidote to the nihilism in US health policy, aka “TINA” thinking: “There Is No Alternative.”ⁱ Not that I think that the Canadian experience is an actual alternative for the US, but observing the choices others have and make reminds me that we too have real alternatives.

Last month marked the twentieth anniversary of the Canada Health Act, a reaffirmation and clarification of the federal government’s role in Canadian health care.ⁱⁱ Constitutionally health care in Canada is a *provincial* responsibility, but the federal government provides significant funding to the thirteen provinces and territories if their health insurance plans abide by five morally relevant principles. The plans must be publicly administered, comprehensive, universal, portable, and accessible. These “universal” national standards are implemented differently in each province/territory making for one intergovernmental health system with a baker’s dozen variants, what we now know as medicare.ⁱⁱⁱ Medicare has become a defining characteristic of Canadian identity, as well as the nation’s most popular, and at the moment I’d say, most controversial, public program.

A year and one-half ago the Canadian Commission on the Future of Health Care released its final report, called *Building on Values*.^{iv} Among its 47 recommendations was one which called for the addition of a sixth principle to the Canada Health Act -- accountability.^v Now one might ask, why is it necessary to add accountability when public administration is already a mandated principle? Doesn't public administration assume accountability? The answers are intimately wrapped up in the story of Canadian health care over the last two decades. The strand of that story that I'll tell begins with an attempt in the early 1990's to involve the public in health systems decision-making by devolving some provincial/territorial authority to newly created regional and local authorities. Strengthened public participation, it was said, would not only make for a more cost efficient and responsive Medicare, it would make for a more fair, accountable, and thus trustworthy Medicare.

Before further examining this Canadian experience, I'll describe two of my conceptual starting points: first, my understanding of health care as a multi-layered relational good, and second, my understanding of justice as similarly relational and participatory.

Health CARE, most would agree, is a social good, but more precisely, it is a relational good. Though some aspects of health care are commodity-like, health care is ultimately about how we relate to one another often in our times of greatest dependence and need. At its most intimate, health care is deeply interpersonal, involving our sick selves in relation to our immediate caregivers, be they paid or familial. But health care is also institutional, structural, and systemic involving a host of economic, political, and professional relationships. And these institutional relations exist within and between local and other communities; they exist at the state/regional levels, at the national/societal levels and globally as well. We bioethicists tend to speak of health care as either an individual good or a social good in the sense of national good. But health care involves a much more complex set of relations involving many different social groups and communities.

Furthermore, we human beings create this relational good we call health care. There is little to nothing essential about our health care systems, rather, they are products of much political, professional, scientific, and moral contestation:

*Western biomedicine//Chinese medicine//homeopathy//faith healing – we create our healing modalities.....

*Medicare - Canadian style//Medicare - US style – we create our health care systems.....

*health care as a right, an entitlement, a market-based commodity, a social responsibility, an instrumental means to equal opportunity..... we create health care's moral meanings and values.

And the “wes” doing the creating are many. Canada's medicare is certainly a national good shaped by the five mentioned principles, and in principle, applicable to all Canadians. At the same time, each of Canada's provincial/territorial health insurance plans reflects different meanings and values negotiated within each province. Pragmatically this means all provinces cover mandated hospital and medical fees, most offer some degree of prescription drug coverage, and a few offer home care, etc. Clearly Canadian health care is the result of social relations at multiple levels.

Justice too is relational: commonly understood as a guide for “right relations” in the distribution of social goods such as health care. But as philosopher Iris Marion Young has keenly argued, this distributive paradigm of justice focuses narrowly on the end stage pattern of distribution – on who’s got what – to the neglect of the social context, including social relations that shape distribution. Often ignored are the seemingly non-distributive elements of justice such as culture, decision-making, and division of labor. Consequently, current social institutions and structures tend to remain assumed and under-examined.^{vi}

We can see this distributive paradigm at work in just health care discourse in the common assumption that universal possession of health insurance means a just health care system; in the relatively unquestioned dominance of the medical profession, and correlatively in the supremacy of the biomedical model of healing. We also see it in our relative neglect of who are (and are not) the distribution decision-makers and the resource allocators. We focus more on who gets what, and little on who decides who gets what. As such we neglect the public in just health care discourse, that is, the public as more than patients; the public as more than observers of others’ decision-making or filers of grievances when there is a problem.

I suggest that fuller, more complex relational and contextual notions of justice are available in political and moral philosophy as well as in Catholic social thought, and I offer three examples here:

First, Michael Walzer’s understanding of complex equality entails respecting understandings of social goods in political communities. Here citizens engage with one another to define the social meanings of goods and to determine their distribution. Says Walzer:

We are all (all of us) culture-producing creatures; we make and inhabit meaningful worlds. Since there is no way to rank and order these worlds with regard to their understanding of social goods, we do justice to actual men and women by respecting their particular creations. And they claim justice, and resist tyranny, by insisting on the meanings of social good among themselves.^{vii}

Second, each element of the tripartite Catholic understanding of justice – commutative, distributive, and social justice - governs a particular realm of human interactions. Commutative justice governs “private” interpersonal relations while distributive justice attends to society’s obligation to persons. “Social justice,” says moral theologian David Hollenbach,

is a measure or ordering principle which seeks to bring into existence those social relationships which will guarantee the possibility of realizing the demands of distributive justice. This means that it calls for the conditions which are necessary to assure that the minimum human needs of all will be met and which will make possible social and political participation for all. In other words, social justice demands that the institutions of society be ordered in a way that makes it possible to protect the social and personal rights of all.^{viii}

Here, social justice is in a sense “prior” to distributive justice as it guides the social relationships and institutions needed to ensure the just distribution of goods.

Finally, and simply, Young asserts that social justice “requires that each person should have the institutionalized means to participate effectively in the decisions that affect her or his action and the conditions of that action.”^{xix}

These three conceptions of social justice point to participation as a key element in justice, and thus just health care: participation in creating and respecting multiple meanings and values of health care, participation in creating social institutions that make distributive justice possible, and having the institutional means to participate effectively in decisions that affect one’s life. This suggests a normative criterion for justice - distinct from distribution as currently understood - something we might call, participation in creating the social goods, institutions, and relationships necessary for distributive justice.

Further positive specification of this participatory justice is clearly needed - participation can mean anything from input to advise to governance. Here I’ll simply suggest that participatory justice requires something like “effective voice,” that is, some level of influence in the outcome, some level of agency or power. As political theorists Elizabeth Frazer and Nicola Lacey ask, “In the non-ideal community of discourse which is the political world, who has the power, not only to speak, but to be heard?”^x If speaking and being heard constitutes effective voice, then not speaking, or speaking and not being heard, is not only ineffective voice, but unjust participation.

In Catholic social justice terms, “a lack of participation” is understood to be marginalization.^{xi} And Young names marginalization as “perhaps the most dangerous form of oppression,” explaining that “Most of our society’s productive and recognized activities take place in the contexts of organized social cooperation, and social structures and processes that close persons out of participation in such social cooperation are unjust.”^{xii} So with this understanding of participatory justice as effective voice, let’s return to Canadian health care and its recent embrace of citizen participation.

“Public administration” as defined by the Canada Health Act means that provincial health insurance plans must be “administered and operated on a non-profit basis by a public authority appointed or designated by the government of the province.”^{xiii} The designated public authorities have typically been the provincial health ministries and in the late 1980s/early 1990s, after several years of declining health budgets, each health ministry undertook sizeable reforms given the increasingly urgent fiscal constraints. Taking a managerial approach, most provinces recommended “spending smarter and spending less,”^{xiv} and advocated increased public participation in policy making and the decentralization of some provincial decision-making “down” to regional and local authorities.^{xv}

The motivations for this move toward citizen participation were many: The public was demanding greater responsiveness on the part of health professionals and policy makers and it seemed that a more effective and efficient health care program could be had if it were based on local needs. Better program coordination and integration, more cost effective decisions, and better fiscal accountability were hoped for. Some saw in public participation the promise of

community empowerment and the promotion of social capital. Others asserted that people have a right, and even a civic responsibility, to participate in their health care system. And finally some saw this as a way for provincial authorities to get some “help” – that is, political cover - in making difficult cost cutting decisions and in sharing the blame for inevitable service reductions.^{xvi}

By the mid-1990s, every province had established some sort of regional health authority, usually boards comprised of appointed local citizens with a varying range of responsibilities including needs assessment, priority setting, service delivery, resource allocation, and revenue raising.^{xvii} Structurally, regionalization looked quite different province to province: Saskatchewan set up 30 district health boards with 1/3 members appointed and 2/3 elected.^{xviii} British Columbia created a two-tier system of numerous local Health Councils overseen by 20 Health Boards, initially fully comprised of lay persons though health care providers were later added.^{xix}

Fast forward to today.....

Many regional health authorities continue today and their political successes and failures have been extensively documented and analyzed., though not their ethical successes and failures. Through the narrow lens of participatory justice and “effective voice,” this ethical analysis asks whether these reforms have created effective voice for citizens, whether structures for effective participation have been designed and constructed, and whether the social relationships necessary for distributive justice have been developed. Though “effective voice” remains ambiguous at this point, I think it safe to say that these reforms, though with their bright spots, have yet to reach the standard of “effective voice.” At their best, these efforts have “democratized the decision-making process,^{xx} and increased local control and better quality decisions.^{xxi} At their worst, these efforts have consolidated the power of professionals or bureaucratic elites thus further marginalizing citizens and communities.^{xxii} Why? What happened?

Simplistically stated, regional health authorities rarely have the tools they need to do the job:

- 1) The boards have been assigned many and vague goals, as illustrated by the laundry list of motivations for their creation.
- 2) Accordingly, accountability is unclear. On the one hand, these regional boards are responsible to the provincial government. On the other hand, board members are there because they are the local folk, and they feel responsible to their local communities and representative groups.^{xxiii}
- 3) Information was lacking on many fronts. Local needs assessments are central to most boards’ activities yet in one survey, only 28% of board members said information about citizen’s preferences was available “always” or “most of the time.”^{xxiv} Mechanisms to communicate with constituents are weak. Similarly, information needed to evaluate services utilization, costs and benefits in an effort to set priorities is wanting.
- 4) Regional boards lack sufficient budgetary authority. Most boards have budgetary authority for institutions, mostly hospitals, but not for payments to physicians and nurses or for prescription drug costs, despite that the latter two combined make up the majority of Canadian

health care costs.^{xxv} Boards ostensibly have the responsibility for the region's health care but lack to fiscal authority for much of it.

5) Health professionals tend to dominate regional decision-making processes. In a study of three provinces in 1995, ¼ to 1/3 of board members were current health care or social service employees,^{xxvi} while in Quebec, nearly 50% of the members on some boards were health professionals.^{xxvii}

6) Lay board members tend to only partially reflect the population demographics of their regions. One survey found “members were generally middle-aged, well educated (almost half had at least 1 university degree) and relatively well off (almost two-thirds had incomes of more than \$50 000). Only 36% were employed full-time, and 22% were retired.”^{xxviii}

Two additional “hindsight” insights are important here:

1) Regionalization and decentralization are two distinct dynamics though they are frequently conflated conceptually and linguistically. Regionalization is the creation of regional/local authorities – and this has clearly happened. Decentralization is a distribution of power from the provinces to the regions - and this power sharing has happened to far a lesser degree.^{xxix}

2) The decentralization of power from the provinces “down” to the regions may also mean the centralization of power “up” from already established local authorities.^{xxx} New regional health authorities have consolidated local hospital boards and services, thus in some cases reduced local participation, local choice of services, and inflamed local resource allocation struggles.^{xxxi} For example, non-urban women in British Columbia report that the regional restructuring of maternity services has not given them greater voice, a greater choice of services, or better access to services but rather they believe that de/centralization threatens all three.^{xxxii}

Now is a particularly challenging environment for effective voice and participatory justice. The movement for privatization and commercialization of the Canadian health care system is gaining momentum. A national election approaches and health care is a central issue. And Canada seems to be of two minds regarding citizen participation.

On the one hand, Canada appears to be retreating toward centralization and consolidation of health care decision-making power.^{xxxiii} In the last decade the federal government's attention to and funding of health care has swung through what two Ontario health officials have called a “manic-depressive cycle in their handling of medicare.”^{xxxiv} It is little wonder that the Canadian Commission on the Future of Health Care, in its recent *Building Values* report, names “dysfunctional intergovernmental relations” and “intergovernmental mechanisms that lack public input” as problems needing resolution.^{xxxv} In response, the Commission recommends new national leadership, “streamlining the intergovernmental process, and... establishing new mechanisms to improve transparency and allow public input.”^{xxxvi} In practical terms this means the creation of a national Health Council of Canada, comprised of governmental and non-governmental representatives that would evaluate the performance of the health care system and provide advice to all levels of government. The Council, which was appointed last December and is just getting underway, is advised to “place a high priority on public input into its work”

through town hall meetings, “extensive use of the Internet,” and “annual check-up[s]” with a representative sample of Canadians.^{xxxvii}

Furthermore, in responding to Canadians’ “deep suspicions about the way governments have managed their health care system and where the money goes,” the Commission proposes adding a sixth principle to the Canada Health Act, accountability. “As the owners, funders, and users of the health care system, Canadians have a right to know how their system is being administered, financed, and delivered, and which order of government is responsible for which aspects of the health care system.” The rhetoric is strong but how will the system become more accountable? ...through public annual reports on system performance provided by the new Health Council.^{xxxviii}

In contrast, some Canadians are working to strengthen the workings of citizen involvement in health care. For example, the Canadian Policy Research Network has a substantial project on accountability of the Canadian health care to citizens.^{xxxix}

So important questions before us include, what is accountability? Is it found in the responsibility of intergovernmental decision-makers? In the deliberation processes themselves? In the transparency of public documents? And how does accountability relate to justice?

In sum, Canada is a helpful lens for seeing the multi-layered relationality of health care, and of *just* health care. Social justice, including effective voice, guides the creation of participatory institutions and structures necessary for distributive justice in health care to occur.

Thank you.

ⁱ David Himmelstein and Steffie Woolhandler, with Ida Hellander. *Bleeding the Patient: The Consequences of Corporate Health Care* (Monroe, ME: Common Courage Press, 2001), 5.

ⁱⁱ Canada Health Act, available at <http://www.hc-sc.gc.ca/medicare/Canada%20Health%20Act.htm>. For background on the Canadian health care system see Malcolm G. Taylor, *Health Insurance and Canadian Public Policy: The Seven Decisions That Created the Canadian Health Insurance System* (Montreal: McGill Queen’s University Press, 1978).

ⁱⁱⁱ The federal government also provides health care funding directly to certain groups including First Nations peoples and veterans.

^{iv} Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada* (2002), available at <http://www.hc-sc.gc.ca/english/care/romanow/hcc0086.html>.

^v Commission on the Future of Health Care in Canada, *Building on Values*, 59ff.

^{vi} Iris Marion Young, *Justice and the Politics of Difference* (Princeton, NJ: Princeton University Press, 1990), 15-38.

^{vii} Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (New York: Basic Books, 1983), 314. Social meanings/values for Walzer are typically national products though he does recognize that multiple meanings/values are possible and must be negotiated through distribution, *Spheres of Justice*, 29.

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- ^{viii} David Hollenbach, *Claims in Conflict: Retrieving and Renewing the Catholic Human Rights Tradition* (New York: Paulist Press, 1979), 152.
- ^{ix} Young, *Justice and the Politics of Difference*, 251.
- ^x Elizabeth Frazer and Nicola Lacey, *The Politics of Community: A Feminist Critique of the Liberal-Communitarian Debate* (Toronto: University of Toronto Press, 1993), 145.
- ^{xi} Hollenbach, *Claims in Conflict*, 86, 199-204.
- ^{xii} Young, *Justice and the Politics of Difference*, 55.
- ^{xiii} Canada Health Act, Section 8, at <http://www.hc-sc.gc.ca/medicare/Canada%20Health%20Act.htm>.
- ^{xiv} R. Sutherland and J. Fulton quoted in Pat Armstrong, et al. in *Exposing Privatization: Women and Health Care Reform in Canada* (Toronto: Garamond Press), 34.
- ^{xv} Sharmila L. Mhatre and Raisa B. Derber, "From Equal Access to Health Care to Equitable Access to Health: A Review of Canadian Provincial Health Commissions and Reports," *International Journal of Health Services* 22 (4): 645-668; Jonathan Lomas, John Woods, and Gerry Veenstra, "Devolving authority for health care in Canada's provinces: 1. An introduction to the issues," *Canadian Medical Association Journal* 156(3): 371-377.
- ^{xvi} C. James Frankish et al., "Challenges of citizen participation in regional health authorities," *Social Science & Medicine* 54 (2002), 1471-72.
- ^{xvii} Jonathan Lomas, Gerry Veenstra, and John Woods, "Devolving authority for health care in Canada's provinces: 2. Backgrounds, resources and activities of board members," *Canadian Medical Association Journal*, 156(4): 513-520.
- ^{xviii} Steven J. Lewis et al., "Devolution to democratic health authorities in Saskatchewan: an interim report," *Canadian Medical Association Journal* 164 (3), 343-347.
- ^{xix} C. James Frankish et al., "Social and political factors influencing the functioning of regional health boards in British Columbia (Canada)," *Health Policy* 61 (2002), 125-151.
- ^{xx} Paul A. LaMarche, "Quebec," in John Dorland and S. Mathwin Davis eds., *How Many Roads...? Regionalization and Decentralization in Health Care* (Kingston: Queen's University, 1996), 124.
- ^{xxi} Lewis et al., "Devolution," 343.
- ^{xxii} Michel O'Neill, "Community Participation in Quebec's Health System: A strategy to curtail community empowerment?," *International Journal of Health Services* 22 (2), 287-301. See also James W. Bjorkman, "Who Governs the Health Sector?," *Comparative Policy* 17 (4), 417; Pat Armstrong and Hugh Armstrong, *Wasting Away: The Undermining of Canadian Health Care*, 2nd ed. (Ontario: Oxford, 2003).
- ^{xxiii} Lomas, Woods, and Veenstra, "1. An introduction to the issues."
- ^{xxiv} Lomas et al, "Devolving Authority for health care in Canada's provinces: 2. Backgrounds, resources and activities of board members," *Canadian Medical Association Journal* 156 (4): 513-520.
- ^{xxv} Frankish et al., "Social and political factors," 128.
- ^{xxvi} Lomas, Veenstra, and Woods, "2. Backgrounds, resources and activities of board members," 513-520.
- ^{xxvii} LaMarche, "Quebec," 120. Jonathan Lomas and Gerry Veenstra, "If you build it, who will come?" *Policy Options*, November 1995, 38.
- ^{xxviii} Lomas, "1. An introduction to the issues," 516.
- ^{xxix} Frankish et al, "Social and political factors," 129.
- ^{xxx} Frankish, "Social and Political factors," 129.
- ^{xxxi} Cecilia Benoit, Dena Carroll and Alison Miller, "But is it good for non-urban women's health? Regionalizing maternity care services in British Columbia," *Canadian Review of Sociology and Anthropology* 39 (4): 373-396.
- ^{xxxii} Benoit et al., "But is it good?"
- ^{xxxiii} Jonathan Lomas, "Past concerns and future roles for regional health boards," *Canadian Medical Association Journal* 164 (3): 357.

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- ^{xxxiv} Terrence Sullivan and Colleen M. Flood, “Chrétien’s prescription for medicare: a green poultice in lieu of accountability,” *Canadian Medical Association Journal*, 170 (3): 360.
- ^{xxxv} Commission on the Future of Health Care in Canada, *Building on Values*, 53.
- ^{xxxvi} Commission on the Future of Health Care in Canada, *Building on Values*, 54.
- ^{xxxvii} Commission on the Future of Health Care in Canada, *Building on Values*, 58.
- ^{xxxviii} Commission on the Future of Health Care in Canada, *Building on Values*, 63.
- ^{xxxix} Cathy Fooks and Lisa Maslove, “Rhetoric, Fallacy or Dream? Examining the Accountability of Canadian Health Care to Citizens,” Health Care Accountability Papers No/1, (Canadian Policy Research Network, March 2004); Mary Pat MacKinnon et al., “Citizens’ Dialogue on Canada’s Future: A 21st Century Social Contract,” (Canadian Policy Research Network and Viewpoint Learning, April 2003); and Mary Pat MacKinnon, “Public Dialogue and Other Tools for Citizen Engagement,” CCARH Conference Workshop, March 12, 2004, (Canadian Policy Research Network). These three reports are available at <http://www.cprn.org>.