

Bioethics' Lack in Relation to Person-Centred User-Driven Health Systems Planning: A Call for Change

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There is a curious lack of interest – on the part of policy makers, but also of bioethics scholars – in service users' (i.e., patients') involvement in health systems planning. This is evident in the conspicuous lack of service user participation in many forums of decision making regarding health systems planning, e.g., government committees, hospital boards, and clinical teams' quality improvement working groups. A current example in Canada is the proposal of Bill 10 in Quebec [1], which focuses on considerable reductions in health administration, presumably both to reallocate resources for more and better health care and to secure needed cost savings. Many have deplored that the participation of service users in this system overhaul is neither sufficiently secured nor encouraged. A similar lack of involvement is evident across the Canadian provinces and territories, as well as in other countries. Indeed, the veteran slogan “nothing about us without us” used by various patient rights movements still seems to go relatively unheeded when it comes to health systems planning (whereas “nothing about me without me” is a better established principle, thanks to the recognition of the importance of the involvement of individual service users in their own health care planning).

There are various ways to advance service user participation in health systems planning, ranging from outright political protest through to public and other educational approaches, to specific resourcing of such service user participation. Yet, a culture shift may be necessary for the health care system to support such participation. An example of such a shift is person-centred mental health care, which is largely driven by the recovery movement and related notions [2] and which actively encourages the involvement of people with serious mental illness such as schizophrenia [3]. In order to uphold choice of service users in mental health systems planning, I have promoted the participation of mental health service users (and their social supports, such as their families) in all decision making forums of my Health Authority's Mental Health and Substance Use program, by establishing and chairing a person-

centred steering committee composed of services users, their family members and internal and external partners. This committee reports to the program's Quality Council group, and proactively as well as reactively, works on various initiatives. For example, the committee recently drafted a patient bill of rights for the program.

This culture shift is needed in bioethics as well, so that bioethicists become more vocal advocates for person-centred user-driven planning throughout the health system. The lack of attention to this issue by bioethics is somewhat puzzling, given that the development of the field was influenced largely by the recognition that human health research until the 1970s did not pay much (if any) attention to personal choice of research participants. This was manifest in infamous research such as the Nazi medical experiments and the Tuskegee affair (where for decades American public health officials did not inform African Americans with syphilis that antibiotics had become available to treat them in order to observe the natural course of this disorder). Fortunately, soon after legislation was put in place to uphold the primacy of informed consent in research, the standard was expanded to health care more generally. Indeed, at least theoretically, consent and refusal in relation to one's health care are recognised in all Western jurisdictions – and in many others as well.

There are of course caveats to the push for user-driven health systems planning, including the potential for conflict with the movement towards evidence-based decision-making. Not every choice of service users (or anyone else, for that matter) leads to positive outcomes and systems improvements, even if it is well informed and robustly discussed. Thus, there is a need for more research on person-centred user-driven health systems planning. I believe that bioethics has a key role in facilitating such research and related developments, e.g., by using its knowledge of pertinent matters, such as the principle of self-determination and its balancing with other bioethics principles. The time for bioethicists to become involved in discussions of person-centred user-driven health systems planning has come.

List of References

1. Anonymous. 2014. [Gaétan Barrette tables bill to overhaul Quebec's health care system](#), *CBC News Montreal*. 25 September.
2. Rudnick, A. (ed). 2012. [Recovery of People with Mental Illness: Philosophical and Related Perspectives](#). Oxford: Oxford University Press.
3. Rudnick, A. & Roe, D. (eds). 2011. [Serious Mental Illness: Person-Centred Approaches](#). London: Radcliffe.