

Comments on “Genome: Moral Choices and the Polity”

Peter W. Van Arsdale¹

I remember clearly the day in 1980 when my University of Denver colleague, Alan Gilbert, rushed into my office and exclaimed: “My brother just won the Nobel Prize!” Indeed, Walter Gilbert had, for his discoveries regarding DNA sequencing methods. These discoveries, and those of others to follow, paved the way for the Human Genome Project. Yet, while this project apparently spurred the accompanying article by Thomas Fitzgerald, it in no sense came to dominate it. Rather, Fitzgerald has written a highly heuristic piece, one that – appropriately – raises more questions than it answers.

I believe that Fitzgerald has written his article so that it can – and indeed must – be read and interpreted on two levels. On the surface, he adroitly (albeit at times in diffuse fashion) shares a bit of information about the Human Genome Project and a lot of information about the ethical issues it raises. The biotechnical information he presents complements the biomedical, and indeed both demonstrate solid understandings on his part. Information system issues and elective surgery issues, both mentioned briefly, exemplify these two fields, respectively. However, Fitzgerald also writes under the surface (*sub rosa* if you will). It is here that he really shines. Genome analysis becomes a metaphor for philosophical discourse, crossing fields as diverse as politics and religion. Discovery of the most minute detail of chromosomal structure becomes a metaphor for human introspection and ethical self-reflection.

For me, the ethical reflections translate directly and dramatically into themes useful in my work. At the Colorado Mental Health Institute (a psychiatric hospital), where I head the Program Evaluation Department, the clinical staff confront psychiatric dilemmas in their work with patients (all of whom are severely mentally ill). Through the institute’s Ethics Committee, which I co-chair, we confront ethical dilemmas, involving patients, staff members, and institutional processes. Some of the more complex dilemmas, presented to us as actual cases (referrals/consultations) involve all three of these elements. Early on, a primary committee mandate became analysis of these cases – in most instances

shared anonymously and in all instances shared voluntarily – with the hope that our findings would help educate ourselves and our colleagues regarding bioethics. Perhaps, some of us thought, we would even be able to help shape the hospital’s “organizational bioethical culture.”

A harsh reality struck. As we attempted to reach out with these messages, we were (with a few notable exceptions) rebuffed.

Our committee does not yet fully understand why, but we have become increasingly introspective and reflective. We have regrouped, reassessed, re-analyzed. All of the following questions, some paraphrasing Fitzgerald quite closely, came to me as I reviewed his article. All are proving exceptionally useful as I help wrestle with the role our committee might play:

- C What are the boundaries of anonymity and confidentiality?
- C Who ‘owns’ the information we obtain through our inquiries? Who sets the agenda?
- C Given the enhanced knowledge that such inquiries engender, what are our obligations to others?
- C What ethics resources should be made available in an institution that is attempting to be ‘just and caring’?
- C Who gets to participate in the debate over ethics? Are patients truly invited in?
- C How is policy transformed into procedure, procedure that is both humane and ethical?

Fitzgerald implies that genome analysis does not simply involve human systems technicians, it involves human systems thinkers. Similarly, at the Colorado Mental Health Institute, our Ethics Committee is attempting to create -- and certainly involve -- “ethics thinkers.” Our

earlier efforts at case consultations were more like the work of technicians. I thank Fitzgerald for allowing me this insight.

Notes

1. Peter W. Van Arsdale is head of Program Evaluation at the Colorado Mental Health Institute, Ft. Logan; Adjunct Professor at both the University of Denver and University of Colorado; board chair of the non-profit Center for Cultural Dynamics, and president-elect of NAPA.