

The tyranny of 'genethics'

Leigh Turner

Whether you work in bioethics, medical anthropology, science and technology studies or health law, if you have an entrepreneurial frame of mind, now is an excellent time to cultivate a 'genethics' research agenda. Around the world, ethics and policy centers related to genetics are proliferating. In Australia, Canada, the United Kingdom, the United States and many other regions around the globe, research teams are pursuing various projects on ethical and social issues related to genetic testing, genetic screening, genetics databases, germ line gene therapy, 'cloning,' xenotransplantation and embryonic stem cell research.

Clearly, important ethical, legal, social and psychological issues are related to genetics. Scholars, policy makers and legislators rightly worry about how access to genetic information might lead to discriminatory practices in the workplace and in the provision of health insurance. Genetics research raises important questions concerning privacy, confidentiality, stigmatization, individual consent, community consent, resource allocation, access to genetic testing and screening, and intellectual property. There is a need to develop analyses, policies and practice guidelines that might potentially influence physicians, researchers, regulatory bodies and legislators. Still, we need to consider whether placing such an emphasis on 'genethics' themes ignores other important ethical, legal and social issues.

Between 1990 and 1999, the Ethical Legal and Social Issues (ELSI) Research Program of the National Human Genome Research Institute (Bethesda, MD, USA) spent \$58.3 million on ELSI funding. Over that same period, the ELSI Branch of the US Department of Energy spent \$18.5 million.

*Leigh Turner is in the Biomedical Ethics Unit, Department of Social Studies of Medicine, Faculty of Medicine, McGill University, 3647 Peel Street, Montreal, Quebec H3A 1X1, Canada, and at Montreal General Hospital, 1650 Avenue Cedar Montréal, Québec, H3G 1A4, Canada. In 2003–2004, he is a member at the School of Social Science, Institute for Advanced Study, Einstein Drive, Princeton, New Jersey 08540, USA.
e-mail: turner@ias.edu*

The yearly expenditures for 'ELSI' research might just look like chump change to you if you work outside the humanities and social sciences. However, if you are an anthropologist or bioethicist, government-funded genetics research programs are the wealthiest 'sugar daddies' you are likely to find.

Genethics is hot. Genethics is sexy. Genethics is generating a lot of poorly designed, repetitive, marginally useful research. Genethics is obscuring the careful consideration of other equally or more pressing social issues. The availability of funding for genetics research is attracting researchers who—in the absence of this cornucopia of financial resources—would likely never consider pursuing scholarship in this area. It is hard to believe that pure intellectual fascination or a sense of civic duty are the only factors prompting so many scholars from anthropology, sociology, media studies and bioethics to pursue genetics-related research.

The problem with this focus is that a vast number of important social issues are neglected by scholars who might otherwise dedicate their careers to more pressing social concerns. For example, although many homeless individuals have psychiatric disorders, are meaningful solutions to the homeless problem plaguing many cities in North America really going to be provided by molecular biology and psychiatric genetics? Are famines and malnutrition in developing nations going to be solved by the introduction of transgenic crops rather than by addressing broader issues concerning the global distribution of basic human resources? Do we need developments in genetics to reduce global mortality and morbidity from the use of heavily advertised tobacco products? Can we expect geneticists to provide meaningful social responses to the widening gap between wealthy, resource-rich, developed nations and poor, developing nations? Can any properly informed individual think that AIDS has a solution rooted solely in genetics rather than in a multi-pronged effort involving the provision of contraceptives and preventive measures, better education, better job opportunities and greater equality between men and women? Many of the great social problems facing the world today are not going to be

solved by breakthroughs in genetics. Similarly, the focus on genetics obscures the extent to which most pressing social issues have rather little to do with genetics.

Genetics research is tremendously important. Similarly, ethical, legal and social issues related to genetics are worthy of careful investigation and deliberation. Still, I am concerned that the abundance of funding for genetics scholarship is skewing research agendas and luring scholars away from the study of other topics that are as important, or more significant, than the careful consideration of genetics. Should governments and funding agencies dedicate less funding to 'ELSI' and 'genetics, ethics law and society (GELS)' research? Should far more resources be directed toward the study of profoundly important social issues, such as homelessness and international inequalities in health?

There is little point in attempting to provide a general response to priority-setting exercises that need to be attuned to local needs and circumstances. That said, it is a cause for great concern that so many philosophers, lawyers, bioethicists, media studies researchers, medical anthropologists, medical sociologists and other 'social critics' are throwing their hats into the genetics arena and filling their caps with abundant research funds. My guess is that if the money were not there many of these scholars would turn their attention to social concerns, ethical issues and legal matters that are far more significant than the topics for which they are now preparing grants, writing reports, 'building capacity' and 'teaching-the-teachers.'

As someone who works within the medical school of a research-intensive university, I understand as well as anyone the pressure to obtain funding for scholarly research. Nonetheless, I am concerned that the financial carrots offered by government agencies, companies and philanthropic foundations are being consumed by scholars who know there are more important topics deserving their attention.

Ten years ago, the big money in bioethics was in the study of ethical, legal and social issues at the end-of-life. We will see how many ELSI and GELS researchers continue to ply their trade when the next big thing comes along. Neuroethics, anyone? 