

天平上的基因：民為貴、Gene為輕

Giunn-Rong Yeh et al., *tianping shang de jiyin: min wei gui, Gene wei qin* [Genes on the Scale]

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Finding the Missing Link Between ELSI and STS

Ever since James Watson set aside between 3% and 5% of his annual Human Genome Project budget¹ to promote the study of the ethical, legal, and social issues surrounding the sudden availability of genetic information, the field of American bioethics has gained a new momentum. While it was first associated with the development of the biomedical sciences, this newly remodeled field, commonly abbreviated as “ELSI,” has obtained the fame around the world and become a shibboleth for any science or technology project determined to earn public trust or at least to appease potential critics. By attaching an ELSI component to a science or technology project, researchers hope to have a hold over the ethical, legal, and social effects of the technology being developed (McCain 2002; National Human Genome Research Institute 2004).

Taiwan’s first ELSI program was launched in 1998 as a part of what later became the National Research Program for Genomic Medicine (NRPGM), with strong institutional support from the National Science Council, the country’s primary funding agency, and other governmental departments. As in other countries, Taiwan’s ELSI programs now extend to areas of science and technology beyond biomedical research. For example, the *National Science and Technology Development Plan of 2009–2012* adopted by the Executive Yuan requires that every “national science and technology program,” from research on agricultural biotechnology to telecommunications, is obliged to allocate a part of its budget to ELSI studies (The Executive Yuan 2009). Such institutional support has, over the past

¹The annual project budget of US-HGP was approximately 135 million US dollars in 1991 and 437 million US dollars in 2003.

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decade, fostered rapid growth in the study of applied ethics, technology law, and other social sciences.

Genes on the Scale developed in that hotbed of innovative thinking. The first author, Jiunn-Rong Yeh, previously acted as the codirector of the NRPGM-ELSI program; with his team of four prominent legal scholars, he outlined a research agenda meant, wrote Wenmay Rei, to “build up an institutional paradigm conducive to the development of biotechnology and to resolve legal, social, and ethical issues related to it” (Rei 2003). Yeh and his team offered a series of lectures meant to increase the scientific literacy of ELSI scholars, and a series of white papers was planned—first steps in an enterprise meant to ensure regular communication between scientists and the public. In the end, the plans remained unfulfilled, but the ideas formed the backbone of the book under review.

The book is divided into three parts. Part I offers a basic introduction to the new genetic technologies. The authors survey genetics from Gregor Mendel’s experiments with peas in the mid-nineteenth century to the sequencing of the human genome in 2003. Next, they provide a brief explanation of how chromosomes, genes, and DNA work, before laying out an array of genetic technologies that seem to be inevitably or at least naturally developed from the basic sciences. The authors then sketch a general picture of the challenges that genetic technologies might pose to society.

In Part II the authors present more detailed discussions of the ethical, legal, and social issues associated with the wave of new biotechnologies. In each of the dozen chapters, the authors explain how the specific biotechnology works and how it is used. They then consider the commonly perceived impacts of the technology on society. Against this backdrop, the authors review the relevant foreign and international regulations as well as the ethical guidelines already outlined elsewhere before outlining regulatory frameworks that might be applied in Taiwan. Among the topics discussed are genetic screening and testing, preimplantation genetic diagnosis, gene therapy, cloning, biobanking research, embryonic stem cell research, and genetically modified organisms and foods. At the same time, readers are acquainted with a range of contemporary ethical and regulatory norms, from UNESCO’s *Universal Declaration on the Human Genome and Human Rights* (1997) to the *Cartagena Protocol on Biosafety* (2000).

In the remaining pages, the authors take a step back to undertake a more reflexive exercise. The authors argue that the strikingly rapid pace with which genetic technology has evolved to manipulate the very nature of life, as well as its uncertain risks and high costs, oblige scientists and policy makers to formulate a regulatory framework that balances progress against security and justice. But rather than drawing up their own specific program, the authors advocate instead an institutional paradigm that would facilitate communication among stakeholders and encourage multiple regulatory mechanisms. The result would mean the birth of a “technological citizenship,” substituting democratic technoscience for credulous faith in or diehard opposition to genetic development.

Genes on the Scale proposes a curriculum that promises to increase the scientific literacy of ELSI scholars and the general public. The book also provides a critical review of the adverse societal effects of genetic technologies while proposing a system of democratic safeguards. However, all too often the authors’ “black-box”

biotechnologies, failing to ask why they were developed in the first place—seem to consider genetic technoscience as a given with an asocial logic. This leads to the conclusion that such a discipline harms society only when it is abused, and questions addressing underlying assumptions tend to be elided. As to the political debates that routinely break out over the allocation of public resources to technoscientific production—they are barely touched. The purview of *Genes on the Scale* is, like most ELSI programs, limited to the repercussions of the development of genetic technoscience after the fact (Macnaghten et al. 2005).

This approach fails to grapple with biopower (Jennings 2003) and stands in stark contrast to a research agenda that acknowledges the constituted nature of technoscience. Such an agenda would be more likely to take into account the political context in which technoscience is produced (Sismondo 2008). Without conflating politics and ethics, it might encourage, for instance, questions about the wisdom of investing public monies in a Taiwanese population-based biobank, and it would certainly oppose any decision made without such considerations. Or at least, as José Julián López and Ann Robertson argued in a recent article, to the extent that the biobanking project or any biotechnology establishment has increasingly been painted as “a vehicle for the pursuit of national economic growth, global leadership and health, it must be debated explicitly and democratically as a *political* project” (López and Robertson 2007). Similarly, a problematic informed by science and technology studies would have critically examined the constituted concepts of health and disease—normal and abnormal—responsible for fueling preimplantation genetic diagnosis, permitting policy makers to devise imaginative ways to help individuals resist the irresistible pressure of the symbolic Other. If the “values” identified in the final part of *Genes on the Scale* are to have real purchase, a politically informed view of technoscience must be brought to bear on any given project long before it is rolled out (Wynne 2005).

Such a political perspective might give rise to “ELSPI,” a hybrid of STS and ELSI. This would mean going beyond the politics of genetic technoscience (Carmen 2004) to unveil the constituted nature of science while promoting a democratic and socially responsible science. If such a synthesis is to succeed, current funding practices must also be changed: appropriating money from scientific projects already underway does not contribute to a reflexive dialogue since the results cannot influence research decisions. A prior and independent commitment to an “ELSPI” process would be a necessary first step.

That said, it is still important to recognize the invaluable contribution that *Genes on the Scale* has made. While chronicling the early ELSI programs in Taiwan, the authors have helped chart the once unfamiliar waters of science governance. Had they not done so, a more prominent role for ELSI would not be possible.

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