Dealing with socio-genetic marginalization in Asia

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Few will dispute that new genetic technologies will become very useful in the prediction of disease and diagnostics. Nonetheless, the health and position of some social groups and individuals may be adversely affected when genetic information is applied in any social context. The concept of socio-genetic marginalization draws attention to the practice of relating the social to the (assumed) genetic make-up of people and brings out its consequences. Certain groups and individuals may find themselves isolated as a consequence of discrimination on the basis of genetic information, and suffer the psychological burden of the knowledge, feelings of social inaptitude, and a sense of financial uncertainty.

By Margaret Sleeboom

During our ICAS3 meeting we explored the ways in which government/state policies affect the fate of the socio-genetically marginal, and the role that researchers play in the process of developing and applying the fruits of genomics. According to TSAI Dujian (National Yang Ming University, Taiwan), consensus building can have a mediating role in Taiwanese genomic policy. So-called 'organic intellectuals' (Gramsci) ought to provide a challenge to the one-dimensional logic of technological progress by developing narratives and group ethics at various levels of society, especially among the socio-genetically marginal. Mediation of new social and ethical views, argues Tsai, is an important way of coping with the biases and stereotypes generated through the use of genetic technologies.

Some reactions to this proposal were sceptical. One member of the audience wondered, who then, are those organic intellectuals, and how could they acquire the power to steer processes that are so obviously part of an unfair global economic and political system? Tsai nimbly handled these rather challenging questions by pointing out the need for a proactive attitude to play a positive role in the government's consensus policy on all socio-economic groups, rather than just pharmaceutical companies and researchers. If academics are going to say something about genomics, argued Tsai, they might as well use their position and skills to voice the views of the socio-genetically marginal, and articulate them with an eye on socio-economic improvement for the weak.

Margaret Sleeboom discussed this issue regarding genetic sampling in Mainland China and in Taiwan. Her comparison of political and socio-economic interest groups involved in public discussion on genetic sampling and the definitions of targeted groups in both states showed that their different cultural and political composition leads to different research regulation and practices. This was demonstrated by the clearly distinguishable ways in which scientists in these two states define their research population, collect their genetic samples, and conduct their research. Thus, different political and cultural views on the 'ethnic' nature of the Chinese and Taiwanese populations not only affected the treatment of sampling populations, which often occupy weak socio-economic positions, but also the scientific outcome of genetic research.

The relevance of the attitude of intellectuals towards the application of new genetic technologies, such as genetic screening, was seconded by NIE Jingbao (Otago University, New Zealand). Nie characterized the Chinese birth-control programme as 'probably unprecedented and unrivalled regarding its massive scale and profound impact'. In its twofold aim to control the 'quantity of the population' and to improve the 'quality of the population', the latter has received increasing emphasis in the 1990s. The ideological underpinning for this socio-genetic engineering programme, argues Nie, draws on various forms of social Darwinism, biological determinism, statism, scientism, utopianism, and reductionism in the sense that it addresses complex social problems in which bureaucracy, controlled by scientists and technicians, plays a considerable role.

Genetic citizenship?

Analogous to 'queer citizenship', in the United States a coalition between patient families, politicians, and scientists has been forged, leading to political activism for 'genetic citizenship' – defending the rights of the genetically disadvantaged – and against genetic discrimination by insurance companies and employers. Kaori MUTO (Shinshu University, Japan) discussed the form that genetic citizenship will take in Asia at the dawn of the 'era of molecular epidemiology': the latter attempts to explain social behaviour through the biological make-up of people. Muto illustrated this by her study on Japanese families with Huntington's Disease, ten years after the identification of the responsible gene. For, also in Asia, molecular epidemiology leads to new forms of health promotion, preventive medicine, and increasingly 'individualized' therapies.

Drawing on interviews with clinicians, excerpts from clinic-based ethnographic observations in India, and narratives of infertile couples from differing social-economic backgrounds, Aditya Bharadwaj (Cardiff University, Wales) showed how couples are caught between societal disapproval of infertility and protracted, financially debilitating medical interventions. Their reproductive agency often takes the form of resisting (seemingly) unending cycles of medical treatment, while, at the same time, they demonstrate an interest in pursuing such treatment so as to alleviate intense familial and societal pressures.

Jyotsna Gupta (LUMC, Leiden) also noticed that genetic diseases in the reproductive field receive great attention. She weighed its benefits against the money that could be allocated to the genetic diagnoses of common diseases such as of thalassaemia and sickle-cell anaemia. More investment in the diagnosis of communicable diseases, such as tuberculosis, would even prevent certain cases of infertility and sub-fertility in both males and females. Nearly all members of our panel agreed that the 'organic intellectual' may be failing to give a voice to the narratives of the socio-genetically marginal. Thus Gupta asked rhetorically, 'in whose interest is a genetic horoscope if a vast Indian majority strongly believes in an astrological horoscope cast at a child's birth?' Disagreement remained, however, as to whether researchers should have a mediating role between the various political and economic interest groups, or try to take distance from the compromising field of genetic politics. <

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