Dealing with Socio-Genetic Marginalization in Asia

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 (SGM) attempts to relate 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 ICAS III meeting we explored the ways in which govern- ment/state policies affect the fate of the socio-genetically marginalised, 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 positive role in the government’s con-sensus policy on all socio-economic issues. According to Tsai nimbly handled these rather chal- lenging questions by pointing out the need for a proactive attitude to play a positive role in the government’s consen-sus policy on all socio-economic issues, rather than just pharmaceuti-cal companies and researchers. If aca-demics 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 marginalised, and articulate their own interest in socio-economic improvement for the weak.

Margaret Sleeboom discussed this issue regarding genetic sampling in Mainland China. In light of the comparison of political and socio-eco-nomic interest groups involved in public discussion on genetic sampling and the definition of targeted groups, both states showed that their different cultural and political composition leads to different research regulation and practices. Both utilised 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 sam-pling populations, which often occupy weak socio-economic positions, but also the scientific outcome of genetic research.

The relevance of the attitude of intel-llectuals towards the application of new genetic technologies, such as genetic screening, was seconded by NIE JING (Jiaotong University, Beijing). Nie characterized the Chinese birth-control programme as ‘probably unprecedented and unrivalled regard-ing its massive scale and profound impact’. In its two-fold aim to control the ‘quantity of the population’ and to improve the ‘quality of the population’, devalued both direct and indirect measures of the responsible gene. For, also in Asia, molecular epidemiology leads to new forms of health promotion, preventive medicine, and increasingly ‘individu- alized’ therapies.

Drawing on interviews with clini-cians, experts from clinic-based ethno-graphic observations, and participants and nar-ratives of infertile couples from diferencing socio-economic backgrounds, Aditya Bhurawaya (Cardiff University, Wales) showed that infertile couples are caught between societal disapproval of infer-tility and protracted, financially debilitat-ing medical interventions. Their reproductice 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 soci-al pressures.

Jyotika Gupta (LUMC, Leiden) also noted that sociogenetic diseases in the reproductive field receive great atten-tion. She weighted its benefits against the money that could be allocated to the genetic diagnoses of common diseases such as of thalassemia and sickle-cell anemia. More investment in the diag-nosis of communicable diseases, such as tuberculosis, would even prevent cer-tain 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 marginalised. Thus Gupta asked rhetorically, ‘is it possible to invent a genetic horoscope if a vast Indian majority strongly believes in an astro-logical horoscope cast at a child’s birth?’ Disentanged 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 com-plicated political and economic interest groups, or try to take distance from the com-

Frequently mentioned in the discussions was the relevance of the attitude of intellectuals towards the application of new genetic technologies, such as genetic screening, to the definition of targeted groups. NIE JING (Jiaotong University, Beijing) characterized the Chinese birth-control programme as ‘probably unprecedented and unrivalled regarding its massive scale and profound impact’. In its two-fold aim to control the ‘quantity of the population’ and to improve the ‘quality of the population’, it devalued both direct and indirect measures of the responsible gene. For, also in Asia, molecular epidemiology leads to new forms of health promotion, preventive medicine, and increasingly ‘individualized’ therapies.

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Genetic citizenship?

A noous of ‘queer citizenship’, in the United States a coalition between patient families, genetic counselors, and scientists has been forged, leading to politi-cal 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 epi-demiology’; the latter attempts to explain social behaviour through the biochemical make-up of people. Muto illustrated this by her study on Japanese families with Huntington’s Disease, ten years after the publication of the responsible gene. For, also in Asia, molecular epidemiology leads to new forms of health promotion, preventive medicine, and increasingly ‘individualized’ therapies.

Dr. Margaret Sleeboom

Rethinking Geopolitics in Central Eurasia

Geopolitics in Central Eurasia (CEA) is today a more contentious issue than ever. Organized crime, ethno-religious conflict, environmental degradation, civil wars, and border disputes reflect the region’s instability. At the same time, Central Eurasia has huge oil and gas resources – the production and export of which are of crucial importance to the region’s economic and political development. The following key questions were addressed at the ICAS panel: (1) How should we conceptualize geopolitics as an approach to studying international relations in the post-Cold War period? (2) What is the nature of geopolitics as practiced by both state and non-state actors in the region? (3) What are the possibilities for and impediments to political stability and sustainable economic development in the countries of Central Eurasia?