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Public Health Care Strategies and Socio-Genetic Marginalization

The increased public and political concern about developments of new genetic technologies has led to an increased scrutiny of the role played by medical experts and public health authorities in their introduction into the health care system. Public discussion, recommendations of professional organizations, legislation, and reliable technological assessment are relied upon to prevent any adverse effects on society. It is also important to organize discussions on an international level. The aim of this ICAS3 panel, confined to developments in China, Japan, India, and Taiwan, is to make a contribution to that effect.

The development of priorities and practices of screening and testing for congenital diseases in different societies varies. A central question is, what are the health care needs and interests of different population groups with regard to genetic testing, and how are they reflected in health care policies? The health care strategies, priorities, and socio-psychological (de-)merits, and the economic rationale of preventative screening, will be central issues of debate. To start with, a more feasible target would be to aim at a better understanding of the consideration of issues amongst different interest groups. In this spirit, Tsai Duujian (National Yang Ming University, Taiwan) explores the interactions between these groups, as well as the interaction between such groups and the Taiwanese Government. He proposes a concept of participatory democracy that may avoid potential conflicts between technological development and humanistic interest, and could coordinate industry, medical societies, and patient groups in working collectively to shape genonic policy. Kaori Muto’s paper (Shinshu University, Japan) explores the concept of genetic citizenship in her study of Japanese families with Huntington’s Disease. The notion of genetic citizenship will gain importance, as genomics will be increasingly socialized through the development and application of new genetic technologies in time to be effective, especially not on a global scale. To illustrate this point, Jing-Bao Nie (University of Otago, New Zealand) discusses the Chinese eugenic project, which relies on ideologies such as social Darwinism, biological determinism, Stalinism, and scientism for its execution, and is reductionist in addressing complex social problems. Nie considers the possible damaging effects of these ideologies, such as the further marginalization of the vulnerable, genetic victimization of the innocent, and the encouragement of authoritarian state policies and technocracy.

To summarize, the issue of socio-genetic marginalization in Asia and the world raises critical questions about the nature of the new relationships between science and society. It is not just a matter of technology and its implications, but also of values and beliefs, social and cultural structures, and political processes. Understanding these relationships is crucial for the development of strategies that can address the challenges posed by the new technologies, while also ensuring the well-being of all individuals involved. The aim of this panel is to contribute to this important conversation, by engaging in discussions on how to approach the development and implementation of new genetic technologies in a responsible and ethical manner, taking into account the diverse perspectives and experiences of different societies and cultures.