

Public health care strategies and socio-genetic marginalization

Article (Published Version)

Sleeboom, Margaret (2003) Public health care strategies and socio-genetic marginalization. IIAS Newsletter (31).

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/57852/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

Copyright and reuse:

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Public Health Care Strategies and Socio-Genetic Marginalization

Agenda >
General

19-22 August 2003
Singapore

By Margaret Sleeboom

The point of departure is the concept of socio-genetic marginalization in Asia. It draws attention to the consequences of the practice of relating the social to the (assumed) genetic make-up of people, even when the relevance of such a connection is doubtful. After all, it is from the cultural (including the spiritual), socio-economic, and political context that we derive the sources that endow our interpretations of genetic information with meaning. The concept of socio-genetic marginalization, first of all, refers to the isolation of social groups and individuals as a consequence of discrimination on the basis of genetic information. With this in mind, my paper discusses the vulnerable position of ethnic groups in China, India, and Taiwan, when facing decisions about revealing their genetic identity by contributing genetic samples to researchers, often under pressure or in exchange for promises of health care. Socio-genetic marginalization also refers to the 'special' position of socio-genetic risk groups that have to deal with the psychological burden of the knowledge, feelings of social

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.

ineptitude, and a sense of financial uncertainty. Drawing on a large multi-sited ethnographic research project, exploring infertility and medically-assisted conception in India's five major cities, Aditya Bharadwaj (Cardiff University, Wales) examines how a biological inability to reproduce not only disrupts reproductive futures of the infertile but also results in bio-social marginalization. Finally, the socio-genetic marginalization also indicates forms of socio-economic marginalization when, for instance, health care becomes too costly for the socio-economically disadvantaged.

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 regards 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 preventive screening, will be central issues of debate. In this context, Jyotsna Gupta (Leiden University Medical Centre, the

Netherlands) questions the practice in India of diverting vast sums of public sector health funds to studying the burden of genetic disease. A major part of perinatal morbidity and mortality, as well as infant mortality, may be ascribed to undernourishment and malnutrition of both mother and child, and a lack of antenatal and postnatal services. Her paper offers ideas for alternative health care strategies that lie in the sphere of public policy-making and education.

The public debate on genomics must go beyond the mere dissemination of knowledge. Some suggestions on how to organize the debate seem to be unworkable in the short-term. Thus, we cannot expect to realize the ideals of public empowerment, client competency, and democratic decision-making concerning 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 eugenics project, which relies on ideologies such as social Darwinism, biological determinism, statism, 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 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 genomic 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 developments in molecular epidemiology. This will require new strategies of public health care. ◀

Dr Margaret Sleeboom is Director of the Socio-Genetic Marginalization in Asia Programme (SMAP) at the IIAS. m.sleeboom@let.leidenuniv.nl