

## INVITED EDITORIAL "Well-Bear and Well-Rear" in China?

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At a time when a blue-ribbon panel of the American Society of Human Genetics is preparing a statement, for the society, on the issue of eugenics comes this clear and transparent reminder of differing worldviews on the issue. Whereas most of us would presume an almost universal consensus on the abolition of coercive practices and directive genetic counseling, the article by Mao (1998 [in this issue]) reminds us of our own insularity. Indeed, this national report coming from the most recent Wertz-Fletcher survey (China is but 1 of 37 countries surveyed) provides us with an opportunity to reflect on our North American ideal of individualism at all costs.

In a country where historical milestones have been achieved in terms of human survival and where communitarian values prevail, the "eugenic" results are not surprising. As stated in Mao's introduction, "eugenics" is widely understood to mean a coercive policy enforced by the state. Although the responses of the Chinese geneticists certainly indicate a eugenic policy, no indication is given of actual or future state enforcement. Still, policies that reflect widespread sociocultural norms do not necessarily need sanction by the state in terms of enforcement or punishment, since they can be embedded in the very "normalcy" and, thus, compulsory nature of certain practices. This is all the more prevalent in China, where the law and the legal system are not seen as the regulator of social practices but where social harmony and conciliation are favored (David and Jauffret-Spinos 1998).

Interestingly, Chinese geneticists differ, in almost every area of response, from their North American and western European counterparts. Yet, with respect to paternalism, directiveness, and a pessimistic view of persons with genetic disabilities, the Chinese results are not so dramatically different from those of eastern Europe or of South America (Wertz [in press]). Thus, whereas in

North America and western Europe the consensus is against newborn screening for carrier status, the testing of children for late-onset disorders, shared marital decision making before and after conception, and obligatory pre-employment or prenatal screening, other areas of the world take positions based on a collective notion of social duties and responsibilities. Difficult as this attitude may be for geneticists in other countries with more "individualist" approaches, it is not necessarily unenlightened or Hitlerite.

China's adoption in 1994 of the Maternal and Infant Health Care Law is remarkable in that, for the first time in Chinese history, the health of both women and children is provided official state promotion and protection. In the ensuing criticism of this law, this noteworthy aspect has often been overlooked, as a result of political and moral one-upmanship.

Moreover, Mao rightly points out that, in spite of tremendous progress in the basic housing and feeding of the world's most populous country, the motivation of the Chinese policies is also underscored by the lack of a universal health care program. Thus, as in the United States, which also lacks such an approach, those less fortunate recognize that any future children born disabled may not be taken care of properly because of lack of personal means. What, then, distinguishes free and informed consent in individuals who decide not to conceive or who decide to abort for financial and social reasons—decisions that, when collectively measured, may constitute a form of implicit economic eugenics—from a collective, sociocultural recognition of these real-life limitations? Not much, except where such social security, health, and welfare gaps are reinforced through legislation.

Thus, although this law reflects culturally shared norms, and although there may be demographic and economic factors underlying the contentious elements of this law, and although China is not alone in favoring a more interventionist approach with the goal of reducing "deleterious" genes (P. Reilly, T. Gelehrter, I. Gottesman, B. Knoppers, P. MacLeod, M. K. Pelias, and D. Wertz, unpublished data), Articles 9, 10, and 16 of the law do not conform with principles of international human rights and ethics. In spite of praise for the health-care

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aspects of the law, the International Ethics Committee of the Human Genome Organization (HUGO), in its Report on the Law (1997), stated that “[i]t is not appropriate to constitute a physician to be effectively the decision-maker enforcer of state policy with which an individual may disagree.” In particular, the committee maintained that “it will be important to establish a number of basic principles to be applied in the use of such tests. These include: conforming to fundamental human rights norms as established by international law; upholding and defending the precious features of human diversity; maintaining the principle of informed consent to medical procedures affecting those who have, or may in the future develop, ‘defects’ or conditions of a genetic kind; providing to those affected, genetic counseling designed to protect their basic rights and to uphold their human dignity and integrity. In the view of the Committee, these fundamental principles are absent from articles, 9, 10 and 16 of the Chinese Law” (HUGO Ethics Committee 1997). The HUGO Committee called for continued dialogue and the sharing of expertise with China.

This is in the spirit of the recent “Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services” of the World Health Organization

(1998). As mentioned by Mao (1998), these guidelines reiterate the need to respect cultural, religious, and social diversity. At what point does such respect, however, become a form of cultural relativism that renders international human rights and ethics meaningless?

Finally, are these results an illuminating and perhaps shocking illustration of eugenics in China? Perhaps. But is the simple wish of every Chinese parent, “yousheng and youyu” (“well-bear and well-rear”), an integration of immoral state policy or just plain common sense?

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