

Forget cloning sheep and pay attention to China

Patrick MacLeod, MD; F. Clarke Fraser, PhD, MD

Silence is cowardly in the face of what promises to be the death of our science in China and the greatest perversion of genetics the world has yet seen.¹

Perhaps it is time for the referee to call a time-out. For the past 20 years, both in this country and abroad, there has been intense debate among members of the medical genetics community about China's eugenics programs. This debate gained international prominence with the promulgation of a new Chinese law on maternal and infant health,² which came into effect on June 1, 1995. British scientists promptly attacked the law as coercive reproductive legislation.^{3,4} The debate has been fuelled by intense, often passionate and patriotic rhetoric replete with overstatement, factual errors and sometimes overt misrepresentation.

If one takes time to actually read the new law, its intent becomes apparent. Primarily it seeks to "[ensure] the health of mothers and infants and [to improve] the quality of the newborn population" while reducing the burden of disabilities. Among many other provisions under this legislation is the requirement that all couples seeking to marry submit to a physical examination by a physician to "see whether they suffer from any disease that may have an adverse effect on marriage and child-bearing." The diseases include "genetic diseases of a serious nature . . . that may totally or partially deprive the victim of the ability to live independently, that are highly possible to recur in generations to come." Also covered by the law are infectious diseases, such as AIDS, gonorrhoea, syphilis and leprosy, and relevant mental diseases, including "schizophrenia, manic-depressive psychosis and other mental diseases of a serious nature." Physicians performing premarital check-ups are to "explain and give medical advice to both the male and the female who have been diagnosed with certain genetic disease[s] of a serious nature which [are] considered to be inappropriate for child-bearing from a medical point of view." The couple may be married "only if both sides agree to take long-term contraceptive measures" or to undergo permanent sterilization. Couples not satisfied with the results of the check-up may apply for a "medical technical appraisal" (an appeal mechanism). When applying for marriage registration couples "shall produce their pre-marital physical check-up certificates or medical technical appraisal certificates." Diagnosis will be verified prenatally if an abnormality is "detected or suspected [e.g., by ultrasonography or because of family history] after an antenatal examination." If a serious disease or defect is found, the physician gives the couple "medical advice for a termination of pregnancy." Any application to terminate an affected pregnancy or to undergo sterilization must "be agreed [to] and signed by the person concerned." So far, so good. What is troublesome is the requirement that couples identified by this process "shall take measures in accordance with the physician's medical advice."

It becomes apparent that the drafters of this legislation are just now discovering the pseudoscience of eugenics. When introducing this legislation, the minister of public health, Chen Mingzhang, was quoted as saying that births of "inferior quality" are serious among "the old revolutionary base, ethnic minorities, the frontier, and economically poor areas."⁵ These remarks are a troublesome reminder of the beliefs of the early founders of the Western eugenics movement,



Editorial

Éditorial

Dr. MacLeod is with the Section of Medical Genetics, Department of Laboratory Medicine, Victoria General Hospital, Victoria, BC, and is Chair of the Canadian College of Medical Geneticists – Royal College of Physicians and Surgeons Liaison Committee. Dr. Fraser is with the Departments of Human Genetics and Biology, McGill University, Montreal, Que., and is Chair of the Ethics and Social Policy Committee of the Canadian College of Medical Geneticists.

CMAJ 1998;159:153-5



who held that single abnormal genes often determined the occurrence of insanity, criminality, alcoholism, pauperism, mental retardation and prostitution because such conditions showed familial aggregation.⁶ Such beliefs became the basis for various pieces of legislation in Canada, including the Immigration Act (1910), which excluded “mental defectives,” “physical defectives” and those with “loathsome” diseases.⁷ Both Alberta and British Columbia had laws permitting the sterilization, without consent, of the “mentally defective.”⁸ The last jurisdiction to repeal such legislation was Alberta, which did so in 1972; at the time of repeal then-premier Peter Lougheed described the law as something from the Dark Ages.⁹ During this 60-year period the social policy phenomenon of eugenics flourished in Great Britain, Germany, Canada and the US, coming to its most horrific nadir with the Nazi programs, which began with the sterilization of “mental defectives” but extended well beyond to sterilization of those with allegedly hereditary physical deformities, mental illnesses and other disabilities.

There is general agreement among geneticists that imposed restrictions on human reproductive choice are an ineffective approach to reducing the frequency of genetic disorders in populations. Even today, legislators and other social policy planners have little, if any, understanding of the most elementary laws of heredity. The causes of most congenital malformations remain unknown. There is seldom a family history in cases of chromosomal disorders, recessive syndromes, new dominant mutations or even multifactorial conditions. By their very nature, eugenics programs that seek to reduce the frequency of deleterious genes in populations or increase the frequency of advantageous genes would make an insignificant contribution, given the time frames involved.

How, then, to express our opposition to the Chinese law? Various groups of geneticists have taken different positions, ranging from encouraging greater communication, to urging the Chinese government to re-examine and modify the law, to discontinuing exchanges of students, collaboration and participation in meetings, specifically by boycotting the 18th International Genetics Congress, to be held in Beijing in August 1998. The American Society of Human Genetics recently issued a statement that “[n]o one should willingly cooperate with any government or private program intended: 1) to compel or coerce a woman or man to avoid becoming a parent because of genetic status, or 2) to compel or coerce a woman to terminate a pregnancy because of the genetic status of the fetus.”¹⁰ The Canadian College of Medical Geneticists supports

any measures that will improve communications with Chinese geneticists, physicians, and legislators, including the training of students, collaborative research programs, and attendance at sci-

entific meetings, with the aim of helping to persuade the Chinese government to replace its program of negative eugenics with a program of public education, genetic screening, and voluntary prenatal diagnosis.¹¹

There is no question that China is struggling with issues of population health beyond our comprehension in the West. For example, the United Kingdom has 1/20 the population of China but 20 times the number of medical geneticists and counsellors to serve that population. China’s health insurance programs do not cover medical genetic assessments, and the population is largely rural, with little access to the few medical genetics clinics that exist. It has been estimated that there are more than 50 million disabled people in China.³ It is from this perspective that one can understand why social planners might adopt eugenic solutions without any knowledge or understanding of the long-term consequences for the gene pool.

Those who feel that shunning is the best way to exert pressure for change are concerned that the diagnostic techniques and genetic information shared freely with postdoctoral fellows training in obstetrics and genetics in many Western universities could be used, by students returning to China, to harm the very families they should be helping.⁴ But having so recently divested ourselves of eugenics laws and programs, we should not cut off the lines of communication that may help persuade the Chinese to do likewise. A Chinese colleague has informed us that most Chinese officials have never even heard of the disastrous outcomes of previous attempts to impose eugenic laws, in Nazi Germany in particular. The notion that the Chinese government is likely to respond to threats — other than by becoming more isolated — ignores several hundred years of modern history. The strategy of shunning is as flawed as the legislation it seeks to have repealed. It ignores the very real cultural differences between China and the West while reflecting an imperialist mentality, which puts China at a disadvantage.

Changes in practice are far more likely to yield results than efforts to change ideologies. Such changes can be taught. Canada has (or had) a longstanding reputation for being among the most generous of nations in its aid to less fortunate countries. Foreign aid takes many forms. The intellectual resources and the modern tools of cytogenetics and molecular genetics that form the laboratory basis for a standard of prenatal care in the West can be shared as well. With the advent of the Internet we are learning that the medical genetics community is still in its infancy in China, and there is a genuine fear for those who would speak out against the rebirth of eugenics in that country. The Canadian College of Medical Geneticists has chosen not to join European colleagues in their boycott but, rather, to argue for continuing dialogue with our colleagues in China and to speak out against a law not



only doomed to failure on moral grounds but also incapable of withstanding scientific scrutiny. Perhaps most important is our duty to help the nonspecialist distinguish between modern science and modern pseudoscience.

Canada has a long and distinguished record of sharing expertise with China in areas of public health and clinical medicine. Now it is time to do the same with biotechnology. We have a moral obligation to share our historical experiences with social policies that masqueraded as Mendelian principles. We should be talking, not walking away from the issue.

References

1. Morton NE. Hippocratic or hypocritic: birth pangs of an ethical code [letter]. *Nat Genet* 1998;18:18.
2. *Order of the president of the People's Republic of China no. 33. Law of the People's Republic of China on maternal and infant health care*. Legislative Affairs Commission, Standing Committee of the National People's Congress, People's Republic of China, 1994 Oct 27.
3. Western eyes on China's eugenics law [editorial]. *Lancet* 1995;346:131.
4. Clarke A. Eugenics in China [letter]. *Lancet* 1995;346:508.
5. Dickson D. Concern grows over China's plans to reduce number of "inferior births" [letter]. *Nature* 1994;367:3.
6. Friedman JM. Eugenics and the "new genetics." *Perspect Biol Med* 1991;35:145-54.
7. Scriver C, editor. *Genetics in Canadian health care*. Science Council of Canada rep 42. Ottawa: The Council; 1991. p. 75-8.
8. McLaren A. Creating a haven for human thoroughbreds. In: *Our own master race: eugenics in Canada 1885-1945*. Toronto: McClelland & Stewart; 1990. p. 89-106.
9. Nemath M, Johnson B. Nobody has the right to play God. *Maclean's* 1995; June 26:17.
10. Board of the American Society of Human Genetics. *Statement on genetics* [policy statement]. Available: www.faseb.org/genetics/ashg/policy/pol-30.htm (accessed 1998 May 20).
11. Canadian College of Medical Geneticists. *China's eugenics law* [position statement]. Ottawa: The College; 1997.

Reprint requests to: Dr. Patrick MacLeod, Section of Medical Genetics, Department of Laboratory Medicine, Victoria General Hospital, 35 Helmcken Rd., Victoria BC V8Z 6R5; fax 250 727-4295

CANADIAN MEDICAL ASSOCIATION

131st Annual Meeting

Sept. 6-9, 1998
Whitehorse, Yukon

ASSOCIATION MÉDICALE CANADIENNE

131^e Assemblée générale annuelle

Du 6 au 9 septembre 1998
Whitehorse (Yukon)



Registration and travel information /
Pour inscription et information de voyage
CMA Meetings and Travel /
Département des conférences
et voyages de l'AMC
tel 800 663-7336 x2383
fax 613 731-8047
martic@cma.ca

H.G. Pfaff