The 57th session of the UN Commission on Human Rights

Agenda Item 17d Promotion and protection of human rights: Science and Environment

Thank You Chair,

The sequencing of the human genome marks the beginning of a new era of scientific discovery. The application of this new knowledge to medicine provides an unparalleled opportunity to advance the health of all. At the same time, the **ethical, legal and social implications** (ELSI) of genomics have come into sharper focus. Concerns raised about these implications relate directly to the impact of the new scientific advances on the promotion and protection of human rights. This is evident from the strength of public concern about cloning, genetically modified food organisms, the possibility of genetic enhancements and the ethics of genetic research on vulnerable populations.

Several key human rights lie at the heart of ethical, legal and social implications of genomics. These are the rights to:

- Equality and non-discrimination;
- Education, information and participation;
- Privacy, individual autonomy and physical integrity;
- The highest attainable standard of health; and to
- Life, to benefit from scientific progress, to social security, and to an adequate standard of living, including adequate food, water, clothing and housing.

These rights make an impact on both the uses of genomics and the research conducted to discover those uses.

We are in the process of consultations designed to develop an agenda and work plan for WHO in the area of ethical, legal and social implications of genomics, especially for developing countries. Discussions with our regional offices, informal planning groups and other UN agencies are on-going but have highlighted the link between the implications of genomics and human rights. I would like to take this opportunity to expand on the relationship between genomics and human rights by presenting the ethical, legal and social issues that have been raised by our consultations and may form the basis for a new WHO initiative in this area. There are six topics.

The first is the **use of genetics in prevention** which means the introduction of genetic tests and related technologies into communities. This raises questions about equality in distribution of services and discrimination as a result of genetic disclosure.

Many developing countries lack even the most basic genetic services, others have well-developed programs that reach only a fraction of their population. Yet in some developing countries, genetic disorders and congenital malformations are among the top public health priorities. Genetic tests are currently available to detect rare, monogenic disorders and congenital malformations. Recent advances in genomics mean that soon a variety of tests for disease susceptibility will also be available. The ethical and social implications of genetic testing are two-fold:

- The first is to ensure that results of genetic testing do not lead to discrimination, either for employment, insurance or education or to stigmatization of families or communities.

- The second is to ensure that the genetic tests known to be effective in promoting healthy communities are available to all, including those in developing countries.

Failure to address the issue of provision of proven, effective genetic services impedes the right to benefit from scientific progress.

The second issue is **resource allocation**. There is a tendency for pharmaceutical and biotechnology companies to focus their research and development capacity on diseases prevalent in developed countries. This commercially successful strategy has two ethical, legal and social implications for genomics:

- A new, proven, beneficial genetic technology targeted for use in developed countries is often prohibitively expensive for those in developing countries; and

- Diseases that cause high burden in developing countries may be overlooked in the research and development process of many companies. This means that the application of genomics to address serious diseases in low-income countries is often not fully developed.

The right to enjoy the benefits of scientific progress and its applications places obligations on governments to take the steps necessary to conserve, develop and diffuse science and scientific research, as well as ensure freedom of scientific enquiry. Science that targets the risk factors and diseases that effect the majority of the world's population should be supported to ensure that all people benefit from the new genomic technology.

The third component is **capacity building and education**. The right to education, information and participation is at stake here. People living in developing countries need not be left behind by the genomics revolution. Building research capacity in genetics through education/training programs for health professionals and the general public is an important part of a community-based genetic service. The right to seek, receive and impart information on all matters related to health prompts WHO to ensure that the risks and benefits of genetic technology are known to all.

Discrimination and stigma are often discussed as outcomes of making the genetic composition of a community available to governments and/or researchers. Genetic information has a stigma attached to it not only for individuals, but also for families and communities. Genetic information can be used to discriminate against individual and communities that become associated with disease-causing gene(s). Such an association has the potential to create what has been called a "genetic underclass". The trend towards genetic determinism, underlined by media discussion of 'good' *vs* 'bad' genes, needs to be brought back into proper perspective through comprehensive education of health professionals and the general public about the limitations of genetics.

The fifth topic, **ethical conduct of research**, refers to both the behaviour of individual researchers and to the nature of research carried out in developing countries. The ethical, legal and social implications of genetic research include:

- Making sure that quality research designs are used when genetic research is done in developing countries;

- Ensuring that the research reflects the health needs of the participating community; and

- Safe-guarding the dignity, integrity, the right to participate in decisions affecting one's own health, privacy and other relevant human rights of individuals within communities participating in research through informed consent and proper protection of data.

The last issue is **Privacy and confidentiality**. Genetic data represents uniquely private information about an individual and also about a family and a community. There are specific medical situations where it would be unethical not to disclose genetic information to family members. Clearly, there are also unethical uses of disclosed genetic information, especially if it is used to withhold insurance or employment. Privacy and confidentiality concerns differ for genetic information obtained from research, genetic testing services and genetic data banks. Nonetheless, the human rights to privacy, individual autonomy and physical integrity are all at stake whenever genetic data is misused.

In conclusion, we are in the process of developing an agenda and work plan for the ethical, legal, and social implications of genomics that will incorporate the work of nearly all WHO clusters, both at HQ and in the regions. Our Director General, Dr Gro Harlem Brundtland, in a recent lecture to the London School of Economics, set the boundaries for an agenda in genomics when she said, "Our challenge will be fourfold:

- to anticipate the consequences of new discoveries rather than reacting to the effects;
- to assess the ethical aspects of this new knowledge;
- to determine which of the downstream products of this discovery are public goods and therefore should enjoy some protection from commercial exploitation; and
- to ensure widest possible access."

WHO will continue to bring 'the voice of health and human rights' to discussions about the ethical, legal and social aspects of genomics.

Thank you.

NMH/MNC/HGN

10 April 2001