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CONFIDENTIAL

Memorandum to Mr. James P. Grant  
Executive Director of the United Nations Children's Fund (UNICEF)  
from  
Robert Cohen

Background on Genetic Engineering / Diagnostics and Bioethics

New York  
13 December 1992



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1. As modern scientific and medical discoveries continue to extend our power over reproduction, heredity and the fundamental make-up of human beings -- before and after birth -- governments, societies and individuals are confronted with an increasing number of choices, decisions and ethical problems. Dialogue and consensus on these matters are made difficult by the rapid pace of these discoveries, by the vast amount and highly specialized nature of the information being generated, and by the inherent sensitivity of issues that are so near to the core mysteries of human existence.

2. Genetic engineering seems to hold out vast potential for doing good. Who can object to the frost-resistant strawberry, the square (and therefore more easily transportable) tomato, and the oil-spill-eating bacteria, which seem so unambiguously positive and useful? Because they seem so benign and beneficial, such ingenious non-human applications of genetic engineering have been permitted with relatively little serious public debate and scarce government oversight. Their introduction has been a virtual fait accompli. The anti-regulatory, free-market ideology of the Reagan-Bush administrations has constituted fertile ground for the private-sector development of genetically-engineered products, including even the patenting of genes as for-profit private property. While no biological or bacteriological Frankenstein has apparently been loosed yet on the environment, the jury is still out regarding the ultimate safety of genetically-engineered creations, the nature of their long-term impact on the total ecosphere and the degree to which considerations of short-term economic profit could override the long-term public interest.

3. If strawberries, tomatoes and one-cell bacteria raise a degree of ethical and practical concern, human genetic engineering and diagnostics provoke a host of troubling moral, economic, social and legal issues that will take many years to sort out. Given our mandate and priorities, UNICEF will not be expected to take detailed positions on most of these questions any time soon. Nevertheless, genetic engineering is giving rise to new techniques that can relieve suffering, detect and prevent disabilities,

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improve health and the quality of life -- potentially for large numbers of children at an affordable price -- and it will not be possible for an organization like UNICEF to ignore that potential or remain silent in the public debate.

4. At a recent international symposium on bioethics and disability, Mrs. Yolán Koster-Dreese, Vice-President of the Dutch Council of the Disabled, said: "For the first time in the history of mankind it is possible to influence **the form of life:** fundamental involvement both before conception and during pregnancy as well as in the later stages of life is now possible by means of manipulation or replacement. This technical ability must be seen against the background of current medical practices. This medical practice is based on two pillars, namely epidemiology and the urge to treat, to execute a therapy. On the basis of epidemiology it is determined what should be considered as "defective" and current medical training ensures that a doctor will want to treat such defects. This, added to the government view that health is an absence of illness, opens a new Pandora's box".

5. As malnutrition and infection account for a smaller and smaller proportion of child deaths in the world, expectations will increase regarding the prevention of genetic diseases and congenital malformations. Diagnostic techniques have been developed to easily detect a growing number of hereditary disorders. Genetic counselling of couples considering having children, and of pregnant women, is now a flourishing field in the industrial countries. When parents or mothers are found to carry genes which could lead to a disabled or otherwise "abnormal" child, the immediate question arises as to whether or not to become pregnant or, if pregnant, whether to allow the child to be born. While the decision not to become pregnant under such conditions is unassailable, abortion is highly controversial on ethical or religious grounds. The dilemma is even greater now that techniques have been developed to manipulate parental genes to avoid or lower the risk of a "defective" child, and to manipulate the genetic make-up of embryo and fetus outside and inside the womb. Genetic manipulation of newborns and children is becoming possible to prevent or treat certain disorders that are either present or expected to develop in the future.

6. Several practical and ethical issues are apparent. As more can be done at the genetic level, in the perinatal period, to prevent lifelong handicaps, the more demand there will be for such preventive and therapeutic measures. The first question that arises is, who decides what is normal and abnormal, defective and perfect? Will the "perfectibility" of human beings lead to a new eugenics as racist and fanatical as that of the Nazis? Will our new capacity to correct defects only heighten the stigma and isolation surrounding the disabled? Will the high cost of genetic engineering and diagnostics lead to a diversion of funds from programmes to assist the disabled? Will a whole new layer of

knowledge and technology be kept beyond the reach of large segments of the world population? Should limited current resources not be devoted to alleviating hunger, preventing infectious disease and providing safe water and sanitation, rather than to developing techniques which, by their very nature, are applicable only to a few?

7. I would assume that progressive public health will eventually expand and adjust to encompass genetic screening, counselling and even engineering when such techniques become available to large numbers at a low cost. It seems logical that WHO should be charged with keeping the international community informed about new discoveries in this field. However, an international dialogue on the ethical, economic, social, cultural and legal aspects of genetic engineering may require the creation of an inter-agency mechanism to ensure broad, multi-cultural participation and the expertise of a range of specialized agencies. UNICEF, with its long track record of promoting the best interest of the world's children, would have a logical role in such a dialogue. A basic UNICEF approach would naturally require sound and ethically appropriate science and medicine; that new discoveries and benefits be made available to the developing world, based on the broadest participation and informed consent of potential beneficiaries of genetic engineering. The dignity and sanctity of each and every individual child must be preserved and promoted.

8. Given the variety of attitudes, values and ethical and religious traditions in the world, the potential for conflict and controversy is enormous. However, progress on the scientific front has always generated fear and reaction, and it is crucial to separate the good from the bad and ensure that enlightened ethics guide our search for a better life.