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DEPARTMENT OF ANTHROPOLOGY

Feb. 12, 1974

Dr. Fred H. Bergmann
Chief, Genetics Section
Research Grants Branch
National Institute of General Medical Sciences
National Institutes of Health
Bethesda, Maryland 20014

Dear Fred:

This is a follow-up to our telephone conversation in which I indicated to you my feeling that NIGMS could and should take a leadership position regarding the clinical and social impact of the basic research it has been funding. One of the places where basic research findings are applied in clinical practice is in genetic counseling. In August 1972 (N.E.J.M., 287:9) F. Hecht and L. Holmes listed 10 unanswered questions about genetic counseling in an editorial entitled, What We Don't Know About Genetic Counseling. Those 10 questions are still unanswered.

Since that time, many more questions have been raised. Professor James R. Sorensen (Dept. of Sociology, Princeton) has carried out a survey of 496 genetic counselors (a summary appeared in Genetic Counseling, a monthly newsletter, 1:5, October 1973), and has reported a great diversity of belief and practice among genetic counselors. To cite one example, 51 percent of counselors considered galactosemia a "serious" or "very serious" condition, but 49 percent called it only "moderately serious," to "minor". There was a similar diversity of opinion regarding the role or roles genetic counselors should play.

All of the above material cited represents views of counselors (and according to Sorenson's data, 80 percent are M.D.s and of those, 63 percent are pediatricians). But there is almost nothing in the literature that systematically deals with what the counselees are looking for.

You indicated to me that few studies have been proposed for funding that would lead to the development of good study instruments and valid results in evaluating the process and impact of genetic counseling. Further, even where good ones have come along, they have been given such a low priority they stand no chance of receiving funds. Yet NIGMS goes on funding research that will lead to more findings which will be communicated to patients in a process which we neither understand or evaluate. As I suggested to you, NIGMS has the responsibility to see that some evaluation is carried out.

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It is obvious that over the country counseling procedures and counselee populations vary greatly. A study which draws only upon counselors and counsees in a single institution is bound to produce narrow results. Indeed, given the number of variables involved in any foreseeable evaluation and impact study, a large N is mandatory, which means going outside of a single institution. If that is the case, whether the funding mechanism is a research grant or a contract, a good study must be carried out by a consortium of some kind. Otherwise, the researcher who seeks to study the patients and counselors at an institution other than his own is bound to run into severe problems of "territoriality".

One model that you might consider for a well-designed research program on genetic counseling, is that used by NHLI for their SCOR programs. There are heart disease research programs going at a number of institutions around the country, on a contract basis, and one of the requirements is that they help develop and utilize some of the same research instruments and procedures and contribute part of their data to a common pool. Perhaps the first step to take would be to invite potential participants to a workshop or conference to lay out the research questions and explore ways of tackling them. Your office need not make a commitment beforehand to a particular mode of operation but should explore various possibilities and be prepared to present them to the working group.

I would be most interested in participating in such a meeting and working with you and others to lay out the research questions and suggest candidates for participation. As I have suggested to you personally, and in my own proposal, a research program is needed that will creatively draw up objectives against which to measure counseling effectiveness---measures that go beyond the relatively narrow one of reproductive behavior.

I look forward to hearing your response to these suggestions.

Sincerely,



Clifford R. Barnett, Ph.D.
Professor, Anthropology
Assoc. Professor, Pediatrics

CRB;dq

cc. Dr. J. Lederberg