PERSPECTIVES
IN GENETIC COUNSELING

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ASILOMAR EAST

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The "Asilomar East" Conference, held in Williamsburg, Va., April 22-25, was the third in a series of meetings held over the past five years to consider issues related to genetics associate training and the future of the non-M.D. genetics counselor. In 1974, several training program faculty, genetics associate students and graduates met informally at the state conference grounds in Asilomar, California to define the expected capabilities of the g.a. and set training goals.

A second meeting in Sept. 1976—also at Asilomar—was sponsored by the March of Dimes. The purpose of this conference was to examine the role of the genetics associate in the provision of genetic services and to explore means of supporting the new professional. This conference was attended by representatives from federal and state agencies and federal legislative assistants concerned with the delivery of health care, representatives of genetic centers and from various volunteer health agencies. A number of observations and recommendations were made about ways of providing genetic services and the need to expand and improve genetics education to increase both public awareness and numbers of people competent to provide these services. Further recommendations concerned overall planning for genetics associate training and evaluation of the programs and graduates.

Since that time a number of new developments have taken place. Increasing professional self-awareness has prompted genetic counselors to form a national organization and public acceptance of the new professional has been manifested in the National Genetic Diseases Act and in various state pilot projects. These developments have raised new issues: accreditation or licensure, adequacy of training, reimbursement for counseling services, ongoing professional education, etc. It was felt that a third conference was necessary to examine these issues with input from agencies and organizations increasingly involved in the provision of genetic services.

Funding was obtained through the Office for Maternal and Child Health, (DHEW) and in December, directors of four of the training programs (University of California, Irvine, University of California, Berkeley, Sarah Lawrence and Wisconsin) met to plan the conference. A task-oriented format was decided upon, with panels to address four different areas. Funding limited the number of participants, who were selected by the planning committee on the basis of what they, because of their experience, expertise or affiliation could contribute to the various panels. Roughly fifty people participated, including representatives of federal agencies and state genetic disease programs, legislative assistants, directors of genetics centers, planners from health maintenance organizations and private insurance (Blue Cross-Blue Shield), various people concerned with dissemination of information about genetic disease, training program directors and several genetic counselors, including nurses and social workers functioning in genetics teams. Eleven participants were graduates of genetics associate training programs. Of these, five were officers or representatives of the National Society and the group of g.a.'s represented a variety of geographic regions and professional roles. Before the conference, participants were assigned to panels and sent working papers prepared by the planning committee.

Neil Holtzman of Johns Hopkins opened the conference with a keynote address in which he made several thoughtful observations about the responsibilities of the genetics community in assuring that quality service was equally available to all segments of the population. He voiced concern about the numbers of potential carcinogens and mutagens which are daily being added to our environment and stressed the need for g.a.'s to be knowledgeable about these and to recognize their opportunity and responsibility to make observations which might increase understanding of effects of these chemicals.

Following the opening session, which included discussion of the keynote address and some brief debate over the genetic counselor vs. genetics associate terminology, the four panels convened to address their respective tasks. Reports of their recommendations were presented at plenary sessions on the second and third days of the conference for the group at large to affirm or modify, and I will briefly summarize the outcome of each panel's deliberations.

Panel I, which had been organized by Joan Marks of Sarah Lawrence and which was chaired by Arthur Bloom of Columbia, was charged with evaluating the curricula of the existing training programs in view of the experience of practicing genetic counselors and their employers. The intent was to arrive at minimum and optimum curricula which would be uniform among existing programs, would set standards for nascent programs, and would represent the types of skills and training believed necessary for any non-M.D. genetic counselor to function effectively. The curricula at Sarah Lawrence, UCB, UCI, Colorado and Wisconsin were compared and the following recommendations were made:

(1) That a two year program was necessary with a Master's degree appropriately reflecting the training.

(2) That a successful applicant should have the following minimum prerequisites: One year each of general biology, general chemistry, and a behavioral science, and one semester of statistics. Optimally, courses in genetics and organic chemistry would be preferred.

(3) That the following science courses be included in the curriculum:

a) a survey of the principles of human genetics

b) cytogenetics
c) biochemical genetics and inborn errors of metabolism
d) clinical genetics—with discussion of common disease entities
e) a course acquainting the student with medical terminology, format and content of the history and physical, etc.

Two additional science courses were recommended for the optional curriculum:

f) embryology
g) postnatal growth and development.

(4) That the following counseling courses be included:

a) theory and application of interviewing and counseling in clinical genetics
b) social, ethical and legal issues in genetic counseling.

(5) That the following be available on an elective basis:

a) methods in clinical research
b) infant and child development (with emphasis on normal psychological development and developmental tests and measures)
c) time for the student to pursue some area of personal interest in greater depth.

(6) That the following field work be required:

a) 400 hours of supervised clinical placement in a minimum of *2* settings with the supervision being by a *physician actively involved in genetics*. Optimum training would involve the following additional fieldwork:
b) use of community resources
c) rotation through a variety of medical specialty services such as perinatology, developmental disabilities, adult and pediatric genetics.

(7) That the student demonstrate his ability to review the literature on an appropriate genetics topic and be able to summarize it in a scholarly fashion.
(A thesis would satisfy this requirement.)

(8) That the student acquire basic skills in physical assessment (i. e., observation of physical features, anthropometric measurements, dermatoglyphics) and be able to perform clinical photography.

The Panel also generated a statement delineating the skills and expertise expected of a graduate of such a training program and describing service, educational, administrative and research functions which the g.a. could be expected to perform.

The task of Panel II, which was planned by Kenneth Dumars and myself, of U.C. Irvine, and chaired by Charles Epstein of U. Calif. San Francisco was to look at ways of paying for genetics associate activities. It was originally intended that the panel would examine the viability of present funding sources and also explore new sources and job possibilities. A wide variety of agencies and potential employers were represented on the panel, but what evolved was primarily a discussion of reimbursement by third party payors. It rapidly became apparent that payment for genetic counseling was less an issue than payment for genetics services in general. The panel felt it was important to establish a precedent for recovery of costs for genetic counseling and made the following recommendations:

(1) It should be established that genetic counseling represents a properly reimbursible service in and of itself.

(2) Mechanisms should be developed for recovering the costs of genetic services "en bloc."

(3) It is not necessary or desirable at the present time to have genetic counselors recognized as independent professionals for the purposes of billing. Therefore, reimbursement for the services of the genetic counselor should be through mechanisms applicable to professionals functioning within a medical setting and under medical supervision.

(4) In order to ensure that third party payors will regard genetic counselors as properly qualified to give services and be entitled to reimbursement, some verification of the counselor's qualifications is necessary. The panel felt that national certification such as is being considered by the ASHG is more expedient and uniform than state licensure or verification on an individual basis.

(5) Efforts should be made to secure general acceptance of the job classification "genetic counselor" by relevant governmental agencies, hospitals, clinics, and other providers of health services.

(6) It is necessary to convince both public and third party payors that genetic services should be reimbursed. To this end, a proposal should be submitted to Blue Cross/Blue Shield to evaluate the technical and fiscal feasibility and public and professional interest in such coverage. These evaluations are done on a contract basis, and it was felt that either the Health Services Administration or the National Foundation should be approached to support such a study, in the hope that a positive finding would have a "spillover" effect on other medical insurance programs and health maintenance organizations.

Panel III was organized by Joan Burns of the Wisconsin program and was chaired by Allen Crocker of Childrens' Hospital in Boston. The Panel's task was to explore ways of assuring practicing genetic counselors of ongoing education. They saw three distinct, but complementary routes for providing this education:

(1) Attendance at national meetings such as the Birth Defects Meetings and those of the ASHG at least once every 3 years. It was emphasized that employers should view these and other meetings for continuing education in the context of staff development and should be committed to providing time and financial support to enable genetic counselors to participate.

(2) Attendance at Regional Workshops which would be designed specifically to disseminate information regarding developments in the field of genetic counseling and to provide ways of improving counseling skills. It was emphasized that such workshops should involve *all* individuals concerned with genetic counseling issues, not just those coming from G.A. training programs. Five broad areas were deemed appropriate for inclusion in such workshops:

a) updates on new developments in various areas, e.g.: amniocentesis, fetoscopy and ultrasound, the biology of individual disease entities,

b) cytogenetics
c) biochemical genetics and inborn errors of metabolism
d) clinical genetics—with discussion of common disease entities
e) a course acquainting the student with medical terminology, format and content of the history and physical, etc.

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a) updates on new developments in various areas, e.g.: amniocentesis, fetoscopy and ultrasound, the biology of individual disease entities, linkage and gene mapping, dysmorphology, behavior genetics.
b) counseling roles and skills with emphasis on such areas as self-evaluation of effectiveness, factors in counseling in special situations such as amniocentesis or around fatal disease, use and usefulness of Bayesian probability in counseling, personal factors in the counselors reaction to counseling activities.
c) issues in the development of the genetic counseling profession, e.g.: certification, roles for the NSGC, gaps in training, career development, reimbursement for services.
d) developments in the delivery of genetic services, encompassing issues such as the National Genetic Diseases Act, state plans for service delivery, data collection and national registries, new models for the delivery of service.
e) social and legal aspects of genetic disease including issues such as: access of minority and poverty groups, pregnancies saved vs. pregnancies interrupted, legal aspects of the genetic counselor's responsibilities, informed consent, role of the counselor in formulation of public policy, advocacy.

The Health Services Administration was recognized as having a significant stake in the professional status of the genetic counseling field, particularly in view of the 34 G.A.'s now involved in N.G.D.A. programs. Because of this it was felt that HSA might be a source of nonrecurring training monies for workshops. The newly established National Clearinghouse for Genetic Diseases was mentioned as a possible source of curriculum materials, and a definite role was seen for the National Society of Genetic Counselors in planning and sponsorship of workshops.

(3) Participation in local programs at the University or Clinical center. A variety of educational opportunities exist in urban teaching centers in the form of local conferences, rounds, journal clubs and local lectures. It was suggested that genetic counselors in rural and university settings might have exchange affiliations in order to enable the "rural g.c." to take advantage of these opportunities and the "urban g.c." to be exposed to the challenges of the satellite setting. Teaching by the genetic counselor in other departments such as pediatrics, o.b., psychology, psychiatry, nursing and social work was viewed as a means of assuring the g.c.'s own self-education.

In order to promote and guide continuing education activities, the panel proposed a committee for Continuing Education to be comprised of representatives from the NSGC (2), from Universities with GA programs (2), clinical centers (2), and the ASHG (1), nursing (1) and social work (1). Allen Crocker will serve as interim coordinator until a chairperson is elected at the first meeting.

Panel IV, which was organized by Seymour Kessler of U. Calif. Berkeley and chaired by Hope Punnett of Philadelphia, was to develop evaluation procedures for both genetics associate training programs and the job performance of genetics associates in health settings. The panel made four suggestions to aid in assuring the quality of training:

(1) That the content of coursework be documented by a catalogue description and a formal syllabus.

(2) That there should be a written contractual agreement between the training institution and the directors of clinical settings in which fieldwork training occurs, delineating the clinical training goals and assuring formal supervision.

(3) That a written evaluation of the student by the placement director and of the placement by the student be provided at the end of each fieldwork placement.

(4) That students' scholarly projects or theses be made available to other training institutions for review and evaluation.

(5) That the programs should evaluate their students after the first year of training and that those not suited should be urged to seek an alternate career.

Evaluation of graduates after the first year of employment was viewed as a temporary measure to maintain "quality control" until such time as accreditation becomes a reality. The panel suggested that the practicing genetic counselor have a written evaluation by his supervisor with copies going to the graduate's employment file and also being returned to the director of the training program from which the genetics associate graduated. It was felt that the g.a.'s performance of clinical, educational, and administrative duties should be evaluated and that some documentation of commitment to continuing education should be made. It was recognized that of these, clinical competence was hardest to evaluate and the panel suggested direct observation of counseling sessions, case presentations and role playing in simulated patient situations. Also mentioned were chart audits and surveys of patient satisfaction.

Although the need for quality control was recognized, there was a great deal of discussion in the plenary session in response to these recommendations. The fact was raised that no other comparable group of professionals was subjected to this degree of scrutiny, and a number of people viewed the subject of returning evaluations to programs as an invasion of the g.a.'s privacy. No mechanism was established to provide for these evaluations; the responsibility was left up to the individual training programs.

Throughout the panel and plenary discussions a number of other issues were the source of lively discussion. First was the associate vs. counselor terminology debate, of which people rapidly tired. There was general agreement that "genetic counselor" defined a functional role, whereas "genetics associate" was a broader term that reflected all aspects of training.

A topic of much concern was the degree of independence which was being required of some g.a.'s in satellite programs. Some counselors who had been practicing for a number of years felt comfortable functioning relatively autonomously, but more recent graduates and some other participants expressed uneasiness with the lack of access to a qualified geneticist with whom the g.a. could conveniently consult. The questions of legal liability for information given by genetic counselors was a thorny out-growth of this issue.

Concerns were also voiced about the appropriateness of some field work placements and the quality of supervision available for trainees. It was felt that programs relying on extra-mural placements should be sufficiently committed to quality supervision to remunerate those individuals responsible for providing it.

Considerable discord arose over the membership policy of the National Society. Limiting membership to masters-level professionals raised the hackles of several M.D.'s who are genetic counselors and again raised the issue of R.N.'s and others who had been counseling for many years, and those providing counseling around a single disease entity.

Of very real concern to all present was to determine what mechanism would assure that the recommendations which grew out of the conference would be acted upon. It was agreed that the proceedings should be published in a concise form as rapidly as possible and that another meeting should be held in October at the ASHG to monitor progress.

POSITIONS AVAILABLE

Genetic Associate in Charleston, SC. Responsibilities include initial contact with families of clients of the Dept. of Mental Retardation, screening, follow-up and continuing education in coastal region of South Carolina. Salary is competitive. Address inquiries to:

Bill Potts, MS
Greenwood Genetic Center
1020 Spring Street at Ellenberg
Greenwood, SC 29646
Phone: 803-223-9411

One opening for a person with a master's level training as **Genetic Associate**, or equivalent. Should have two years experience in genetic counseling, interviewing, medical records. Will need ability to work with patients and staff and good writing ability. Experience in planning and evaluating research projects is desirable. Responsibilities to include provision of genetic information, participation in genetic counseling clinic (scheduling, interviewing, recording), maintenance of research and counseling files, assistance in evaluation of statewide needs for genetic services and assistance in writing of research reports. Position open August 1, 1979 or later. Salary range starts at $14,200 per year. Write to:

V. Elving Anderson
Dight Institute for Human Genetics
University of Minnesota
400 Church Street S.E.
Minneapolis, MN 55455.
Or call: 612-373-3639

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