PERSPECTIVES IN GENETIC COUNSELING
NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
nsgc
Volume 7, Number 1, March 1985

LICENSURE AND GENETIC COUNSELING

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Convincing arguments can be made both for and against licensure of genetic counselors. Three members of the professional issues committee reviewed the literature to provide members of the NSGC with information about this topic. This is not a position statement of NSGC. We present a summary and analyze the issues as they apply to genetic counselors.

Licensure can be defined as the process by which a legal authority grants permission to a qualified individual or entity to perform certain activities. In the late nineteenth century, individual states began to license medical practitioners to protect the public from quacks and fraudulent practitioners. Benefits from licensure became apparent as other health occupations were included. These benefits included the raising of state revenue from licensing fees, the legitimizing of new occupations, and the controlling of numbers of practitioners and the direction of development of a particular profession (1). Licensure has also been viewed by some as conferring a degree of professional recognition and responsibility (2). Efforts to license health care professionals have expanded; in California, for example, there are now more than 25 separate health-care licenses (1), among them recreational therapists and marriage and family counselors (3).

Levels of Licensure

Theoretically, licensure can be developed on three levels: federal, state, and institutional. The federal government does not issue licenses for practice in any health care profession and has maintained a hands-off approach to issues affecting providers of care. National health policies have tended to address health-care delivery rather than health-care providers (4). Results of a poll conducted by the National Conference of State Legislatures indicate little likelihood of change. This poll of key legislative health leaders failed to show support for a federal effort to supercede state licensing laws that govern nurse practitioners (NPs) and physician's assistants (PAs) (2).

Licensure granted by an individual state or community always involves a legislative act that describes the circumstances under which one can practice a particular occupation, and the functions of that occupation. New tasks cannot be assumed without a change in the law (5). Power to administer the law is usually vested in a board comprised of practitioners from that occupational group or a related field such as the board of medical examiners (6). Consumers may hold board membership but generally do not comprise the majority (5). Board activities may include examining qualifications of applicants, setting standards for practice, investigating complaints, and taking disciplinary action against individuals found to be incompetent or engaged in unethical conduct.

Policies on licensure of individual professions vary from state to state. Individuals possessing a license issued by one state can apply for a license in another state if the states allow reciprocity. Each state's board reviews the application and charges a fee for issuing the new license.

Institutional licensure is an alternative to licensure of individuals. In this system, a state agency grants a license to an institution rather than an individual. An example is hospital credentialling of employees who work in rehabilitation services, intravenous-therapy teams, or respiratory therapy. The institution would then define the functions of the occupation and the activities of the practitioners. These can vary among institutions, thereby reflecting the differing needs of individual institutions. The licensing agency might supply guidelines, but would not mandate qualifications of practitioners. If an institution could not acquire sufficient personnel, it could develop its own educational program (7).

Evaluation of licensure by institutions suggests several problems. A study of 19 hospitals using some form of institutional licensure concluded that the problems of discrepancy among activities of personnel, overlap of functions, and high cost made such licenses unfeasible (7).

When state licensure of individuals was evaluated, several effects were noted (1,3,7). In some cases, cost of entry into an occupation increased when further education was required to qualify for licensure. Other trends included increased income for licensees, increased consumer costs, and limited access to services in some areas. Licensure has also been used as a weapon against encroachment by other providers and has limited innovation in the delivery of care.

Although licensure has not yielded expected benefits in assurance of quality and cost containment, many health professions have sought and obtained licensure. A review of their experiences can provide insight into the complexities of this issue.

Historical Perspective on Licensure

Nurses began to seek state laws to register "trained nurses" in the early twentieth century. By 1923, all states had laws pertaining to licensure of nurses (2). Later, distinctions between registered nurses and practical nurses were written into the laws, and recently nurse practice acts have been amended in many states to define the functions of the nurse practitioner. Nurses in every state are licensed and regulated by state licensing boards (8). Many state licensing boards develop regulations that are based on collaborative relationships between nurses and physicians rather than on nursing practice occurring under physician supervision. With these interdependent relationships also comes the understanding that nurses must be willing to assume professional accountability for their actions in the area of liability (9).

Although PAs have also achieved licensure, their experience is much different from that of nurses. The first PA program opened at Duke University in 1965 in an effort to provide career opportunities to men who were functioning under physician direction. In the early 1970s model legislation was created that recommended state-by-state certification of PAs based upon review of individual job descriptions. This approach, case-by-case review of PA functions, was chosen to minimize legislation that was overrestrictive or quickly obsolete. Experience with this approach was disappointing, and the model was abandoned, even though some believed the flexibility of the approach was advantageous (10).

There are two types of regulation in the licensure of PAs. One is a simple authorization statute that allows physicians to delegate certain activities to PAs. The other, a regulatory statute, places responsibility for PA practice within a regulatory agency, for example, the state's board of medical examiners (8). Most states with regulatory authority require certain educational requirements and/or passage of a national certifying exam (10). Definitions of functions of the PA include mandatory physician supervision and physician responsibility for patient care (11). Boards of medical examiners lack uniformity in requirements for education and experiences and have almost complete discretion to establish rules and regulations governing the practice of PAs in their states. In some states PAs are prohibited from practicing activities of other professions such as dentistry, dental hygiene, pharmacy, and chiropractics (12).

One anticipated benefit of licensure for NPs and PAs has been that it would open the opportunity for third-party reimbursement. Third-party reimbursement of nonphysicians has generally been based upon the comparison of services by nonphysicians as if those services were provided by a physician. Mechanisms of payment may vary with the conditions under which services were provided, whether the employer or the professional was to be reimbursed, and whether the nonphysician's care was valued at the same or a lesser rate than that of the physician (6). Certified nurse midwives and nurse practitioners qualify for some forms of reimbursement in some states; however, the provision of reimbursement is complicated and is available for only certain types of services.

Vol. 7, No. 1, March 1985
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Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial staff, 1984-1985: editor, Joseph D. McInerney; resources, Beth A. Fine; legislation and funding, Edward M. Kloza; book reviews, Joan FitzGerald; counseling case reports, Carla B. Golden. Manuscripts, correspondence, address changes, and inquiries concerning subscriptions should be sent to *Perspectives,* BSCS, The Colorado College, Colorado Springs, CO 80903. See Vol. 6, No. 4, December 1984 for instructions for contributors.

Although some have questioned the benefits of licensure, several other professions are currently exploring its feasibility. The Society for Public Health Education has recommended development of a body of ethics before issues of licensure and malpractice are addressed for health educators. Rather than exploring legislation for licensure of health educators, this organization prepared guidelines for the educational preparation of individuals involved in health education (13).

Physical therapists and occupational therapists are licensed in all states. This authority rests with a board separate from the board of medical examiners. Although all applicants must take a national licensure exam, the passing score and options of oral exams and/or specific work requirements are determined by individual states. Third-party reimbursement is available in some areas if a physical therapist operates a rehabilitation agency and has acquired a provider number (14), which allows the therapist to bill third-party carriers.

The practice of social work is licensed in 35 states, each of which has some type of registration or licensure for certain aspects of social work practice (15). Titles and educational levels for entry to practice vary. In some states social workers may practice autonomously, while in others their practice is on a referral basis only. Examination for licensure varies among states, and a major effort is underway to assure that a common body of knowledge exists in state exams. Some, but not all, states have reciprocity laws that allow boards to review applications for licensure of a social worker licensed in another state (16).

Dieticians have also sought state licensure. In one state, this effort was prompted by the inclusion of nutritional counseling in an act related to chiropractic practice. Opposition to licensure of dieticians was generated by representatives of commercial weight-loss clinics and health food manufacturers and distributors (17). For many years national registration of dieticians has been available through the American Dietetic Association. This, however, does not constitute licensure.

Implications for Genetic Counselors

From the foregoing information, several issues emerge about licensure in the field of genetic counseling. Because genetic counseling services are provided by individuals from a variety of health care backgrounds—including medicine, nursing, and social work—it would be extremely difficult to eliminate the overlapping of tasks performed and to restrict some tasks just to formally-trained genetic counselors. If legislation were written to define the activities of genetic counselors, it is unlikely that the services could be defined in a way that would exclude all other members of the health team from performing those functions. For example, providing primary counseling services to patients is a part of medical care. The licensed physician has traditionally been permitted to work in all health care fields, and efforts to prevent physicians from performing genetic counseling services could result in costly disputes that would have little chance for positive outcome (18).

Another obstacle is a projected need for genetic counseling personnel. One estimate predicts that even if four counselors worked with each medical geneticist, only 5,000 counselors would be needed before the demand would reach a plateau (1). There are currently more than 1.5 million registered nurses (19). The comparatively small number of genetic counselors would make efforts to attract legislative interest difficult.

A third factor limiting the advisability of licensure is the political environment, which favors less governmental regulation of health occupations rather than more. In the early 1970s, the Department of Health, Education and Welfare joined the American Hospital Association, the American Nurses Association, the American Public Health Association, and the American Medical Association in requesting a moratorium on the licensure of additional health occupations (11). National concern about the rising cost of health care makes it unlikely that new regulations would be viewed as a cost-containment measure. Some consumer organizations believe that the public is better able and more willing now to protect itself from inadequate health care, and they are calling for a repeal of current licensing laws (20).

Licensure has been discussed as providing an opportunity for third-party reimbursement of genetic counselors. Current efforts to expand third-party coverage for genetic counseling are occurring in at least two states as a part of the Blue Cross/Blue Shield Genetics Services Benefit Study. It is unlikely that individual counselors, rather than the employing institution, would receive payment. The prospect of third-party reimbursement would be attractive to genetic counselors who wish to enter private practice. Licensure of genetic counselors may provide opportunities to qualify for third-party reimbursement.

Achieving licensure will require that genetic counselors establish the need for state-by-state regulation of the practice of genetic counseling, resolve conflicts with various professional groups that provide genetic counseling, and increase the number of genetic counselors in each state to a level that would make the creation of state regulatory services worthwhile. Continued discussion of this issue will be important in the development of genetic counseling services.

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RESOURCES

The Marfan Syndrome. Reed E. Pyeritz and Julia Conant-Yearsley, 1983

This 17-page booklet addresses questions asked by patients, and the families of patients, affected with the Marfan syndrome. It is written in a sophisticated manner and is comprehensive in its discussion of medical aspects of the Marfan syndrome. Involvement of the eyes and skeletal system is described briefly. Cardiac problems are described in detail and with excellent diagrams. The authors address the need for a multidisciplinary team of medical specialists such as orthopedists, cardiologists, pulmonologists, geneticists, and ophthalmologists as they explain the nature of the symptoms found in people with Marfan symdrome. Surgical and pharmacologic treatments are reviewed. Inheritance of the syndrome is discussed, including the concept of new mutations and advanced paternal age. The booklet closes with a section on the risk of pregnancy to affected women, as well as with brief paragraphs on physicians who should be involved in patient care and current research.

As an informative publication, this booklet is complete and well organized. However, aside from a brief summary of the goals of the National Marfan Foundation, little attention is given to psychosocial issues. The authors state that some people who have Marfan syndrome feel it has had little influence on their lifestyles, while others have made many important decisions based on their diagnosis. A more in-depth discussion about the effect of a new diagnosis of a child or the impact of crisis from death related to cardiac problems might be helpful.

In general, this booklet is informative and helpful; it makes complex physiological descriptions clear and simple. *The Marfan Syndrome* is a useful supplement to a genetic counseling session.

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CASE REPORTS IN GENETIC COUNSELING

Case No. 4

Prenatal diagnosis for the purpose of sex selection has been a concern to genetic counselors since amniocentesis achieved widespread use. A previous case report in *Perspectives* (Case No. 1, Vol. 6, No. 2, June 1984) has prompted discussion between genetic counselors about the negative feelings of both patients and professionals after a second trimester abortion because of unwanted fetal sex. In part, these reactions may be caused by the advanced stage of pregnancy when the abortion is performed. However, the advent of first trimester prenatal diagnosis by chorionic villi sampling (CVS) may preclude the need for a second trimester pregnancy termination. Therefore, CVS will be particularly appealing to patients seeking prenatal diagnosis for sex selection. The two cases presented here illustrate the potential problems of providing CVS to patients for sex selection. Both cases of CVS were among the first 40 cases performed at our institution.

The first case involved a 33-year-old couple from India; the husband is a physician. They have two healthy daughters and presented at 9.5 weeks gestation in their pregnancy. The indication for CVS was "hemophilia" in the patient's brother and maternal uncle. These relatives were said to have lived in India, and, therefore, we could not obtain medical records. The patient had never been tested for hemophilia carrier status, because she "knew that both previous fetuses were female by ultrasound." The husband claimed the couple would terminate any pregnancy of a male fetus. CVS was performed at 10 weeks gestation; the result was 46, XY, normal male. When informed of the sex of the fetus, the patient's husband responded by saying, "Oh, good." The couple has now decided to continue this pregnancy despite the "risk" for hemophilia.

The second case involved a 30-year-old couple from Pakistan who claimed to have had a child with "monogolism"; the child, they said, died in Pakistan. Again, no medical records were available. This is the second pregnancy for this couple, who presented at 9 weeks gestation requesting CVS. The counselor felt that the patient's husband was unduly concerned about the ability to determine the sex of the fetus. The results of the CVS were 46, XX, normal female. The patient's husband telephoned repeatedly, concerned about the accuracy of sex determination and the immediate need for the CVS results in the form of a letter. We telephoned the patient as part of our normal followup and were informed that a "miscarriage" had occurred at about 13 weeks gestation. Because her obstetrician was unaware that this had occurred, we questioned the patient about where she had gone for care following the miscarriage. The patient stated that she had gone "back to Pakistan" for the D and C after her "miscarriage."

There are several concerns in cases such as this: 1) CVS in our institution is a somewhat limited resource. Patients with maternal age indications may be denied CVS due to our full schedule. It would be unfortunate if denials were made because of large numbers of couples who present with possibly fabricated indications; 2) it is possible that patients terminating a pregnancy after sex determination would report the loss as a miscarriage to ensure future access to the test. This may bias the miscarriage rates, which would distort data being accumulated about fetal loss after CVS; and 3) patients who present for CVS with a possible fabricated history are provided with CVS because it is not possible to determine that the genetic risk does not exist. On the other hand, patients requesting CVS for the explicit purpose of sex determination are denied the procedure in most institutions. Thus, patients who are truthful are penalized.

As Ms. Knight pointed out in her response to Case Report No. 1 (Vol. 6, No. 4, December 1984), there is indeed a strain upon the staff from these patients. Not only are our resources strained, but we also feel manipulated by the patient. There is conflict between the nondirective ideal of patients making the best choice for themselves, and the counselor's own feelings about the abortion of a normal child of the "wrong" sex against a backdrop of much greater tragedy in other families. Where can guidelines be drawn? In our institution we will not withhold information about the sex of the fetus after CVS. Due to the possibility of maternal contamination with CVS, we cannot be absolutely certain that test results showing a 46, XX fetus are correct.

We anticipate an increased demand for CVS for sex selection, because it is a first trimester test. Before CVS becomes more widespread, it may be helpful to devise a policy within each genetics unit to handle CVS for sex selection.

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BOOK REVIEW

Drugs in Pregnancy and Lactation, by Gerald G. Briggs, Thomas W. Bodendorfer, Roger K. Freeman, and Sumner J. Yaffe, Baltimore, Waverly Press, Inc., 1983, 415 pages, $45.50.

This relatively new resource for use in determining teratogenic risk is a welcome addition to other catalogs by other authors. The book is very easy to use, and any practitioner faced with questions of the effects of prenatal exposure will appreciate the alphabetized drug list and cross indexing. The use of different type sizes and obvious sectioning in the body of the book facilitates skimming and places the information at your fingertips. Information about specific drugs is current for the most part, although, like other resources on the same subject, many drugs have been omitted and some medications not found elsewhere are included.

Each drug is given a category risk factor (A,B,C,D, or X) that may influence the user's evaluation of the drug. I am concerned that the busy physician in private practice who is unfamiliar with the complexity of teratogenicity determination may be tempted simply to note the risk factor classification and provide his or her patients a risk of abnormality without considering all of the published studies of the drug. I think the risk factor has been exaggerated for some drugs classified by the authors as potentially or conclusively teratogenic (e.g., Valium), when, in fact, prospective data have not substantiated an increased risk of abnormality. A statement by the authors about referring particularly complex questions to individuals familiar with teratogenic risk data (e.g., a genetic counselor) could have been included in the introduction to aid practitioners in educating their patients about potential risk.

The book is very similar in organization to Dr. Tom Shepard's *Catalog of Teratogenic Agents* and is certainly as useful. However, due to gaps in both Dr. Shepard's book and the book under review, one still needs to rely on multiple resources when faced with questions of teratogenesis. And, of course, most references are out of date as soon as they are published, and one must still gather current information from other sources for complete risk estimation.

I recommend this book for all practitioners in the field of medical genetics and suggest it as an augmentation of other reference books on the subject rather than as a replacement.

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NSGC NEWS

The NSGC education committee is seeking suggestions for a theme for the 1986 NSGC education conference, to be held in Philadelphia. Please send suggestions for themes and speakers to: Beth A. Fine, Division of Medical Genetics, 3 K & K, Michael Reese Hospital and Medical Center, 31st Street & Lake Shore Drive, Chicago, IL 60616, phone: (312) 691-4436.

ANNOUNCEMENTS

The second annual Medical Genetics and Birth Defects Institute will be held on the campus of Rhode Island College, Providence, Rhode Island, during the week of 23-28 June 1985. For further information, please contact Dr. John A. Bucci, acting dean, School of Continuing Education and Community Service, or Tamah L. Sadick, PhD, conference coordinator at: (401) 456-8210. Among the speakers are Jessica Davis, MD; Leonard Heston, MD; Ming Isuang, MD; Dianne N. Abuelo, MD; Gail Barsel-Bowers, MS; Robert Greenstein, MD; Richard Mahoney, PhD; Thomas Brewster, MD; Philip Reilly, Richard Myers, Gertrude Berkowitz, Leonard Coustan, Donald Goldstein, Wayne Miller, and the Reverend David Ames.

CORRECTIONS

The article titled "Genetic Counselors on Institutional Ethics Committees and Infant Care Review Committees," by J. L. Benkendorf and T. K. Kushner (Vol. 6, No. 4, Dec. 1984), contained two misprints: (1) the section on infant care review committees should state that DHHS recommendations call for one representative from each category, rather than two, as indicated for some categories; and (2) the correct address for the National Center for Institutional Ethics Committees is: American Society of Law and Medicine, 765 Commonwealth Avenue, Boston, MA 02215. We apologize for the confusion. (Ed.)

POSITIONS AVAILABLE

Genetic Counselor: The Swedish Hospital Medical Center, Division of Perinatal Medicine, Seattle, Washington, has a full-time, permanent position for a board certified/eligible genetic counselor. The counselor will work in a prenatal diagnosis clinic, performing all counseling for patients considering amniocentesis or other prenatal diagnosis procedures. The position offers the counselor an opportunity to assume significant responsibility in patient management and counseling. The prenatal diagnosis clinic sees well over 1,000 patients per year and is a major referral center for the Pacific Northwest. The counselor will work with one other genetic counselor, four obstetricians, cytogenetics lab, alphafetoprotein lab, and a full support staff. This is a permanent, full-time position that offers competitive salary and complete benefits package. For further information contact: Robert Resta, MS, Division of Perinatal Medicine, Swedish Hospital Medical Center, 747 Summit, Seattle, WA 98104, phone: (206) 386-2101. Swedish Hospital Medical Center is an Equal Opportunity Employer.

Genetic Associates/Counselors (2): Two positions for genetic associates/counselors will become available beginning in July 1985, in the Clinical Genetics Center, University of Wisconsin - Madison. Applications are invited from individuals who have or anticipate having a master's degree in genetic counseling, who are certified or eligible for certification by the American Board of Medical Genetics, and who wish to join a large, active, comprehensive clinical program (currently including seven genetic associates). Successful applicants will become part of an integrated program including direct services (general genetics, prenatal diagnosis, developmental disabilities, skeletal dysplasias, teratogen counseling, stillbirth evaluation, sensory deficits, single disease clinics, etc.), education, outreach activities, and clinical research. Salary commensurate with background and experience. To ensure consideration, an application should be submitted before 1 May 1985 to: Renata Laxova, MD, PhD, Director, Clinical Genetics Center, University of Wisconsin, 1500 Highland Avenue, Madison, WI 53706. The University of Wisconsin is an Equal Opportunity/Affirmative Action Employer.

Genetic Associate: Tired of the cold? Come to sunny Florida. A faculty position is available for a full-time genetic associate. Primary responsibilities will include patient care, coordination of regional genetic clinics, participation in specialty and prenatal diagnosis clinics, and education of professional and lay groups. Applicants should be board eligible or certified as a genetic counselor with the American Board of Medical Genetics. Submit curriculum vitae and the names of three references to: Boris G. Kousseff, MD, Department of Pediatrics - Box 15-G, University of South Florida College of Medicine, 12901 North 30th Street, Tampa, FL 33612.

Genetic Counselor: A part-time position in genetic counseling is available at the Elizabeth General Medical Center. Primary responsibilities include general clinical genetics serving pediatrics and obstetrics, participation in coordination and administration of clinic, public education programs, outreach clinic, and family support groups. Applicants must have a master's degree in genetic counseling and be board eligible/certified by the American Board of Medical Genetics. Submit curriculum vitae and names of references to Esther Silbey, MS, Genetics Department, Elizabeth General Medical Center, 925 East Jersey Street, Elizabeth, NJ 07201, phone: (201) 558-5485.

Genetics Associates, Incorporated is pleased to offer the following opportunity: Genetic counseling centers are being opened in various cities and are being staffed by qualified genetic counselors who are given the opportunity to share in the ownership of their center. The applicant can select the city in which he or she wishes to operate. Qualifications sought include formal training, practical genetic counseling experience, and a sense for business operations. Please forward a vitae, including the names, addresses, and telephone numbers of two references to: Richard J. Warren, PhD, Genetics Associates, Inc., 7245 S.W. 87 Avenue, Miami, FL 33173. Genetics Associates, Incorporated is an Equal Opportunity Employer, involved in medical genetics services since 1974.

Genetic Counselor: Position available 1 September 1985 for board certified genetic counselor with a minimum of two years of experience, preferably in an obstetric-related setting. The counselor will be working within the Division of Perinatology, Section of Genetics of the Department of Obstetrics. We are the largest perinatal center in the Philadelphia area, with more than 4,000 deliveries per year. There will be significant traveling involved to satellite locations in the greater Philadelphia area. Salary dependent on training and experience. Please send C.V. to: Dr. Linda Dunn, Department of Obstetrics and Gynecology, Pennsylvania Hospital, 8th and Spruce Streets, Philadelphia, PA 19107, phone: (215) 829-3476.

JOBS HOT-LINE NUMBER
Linda Nicholson: (302) 651-4234

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