

Genetic Counselors' Scope of Practice

This “Genetic Counselors Scope of Practice” statement outlines the responsibilities of individuals engaged in the practice of genetic counseling. Genetic counselors are health professionals with specialized education, training and experience in medical genetics and counseling who help people understand and adapt to the implications of genetic contributions to disease.¹ Genetic counselors interact with clients and other healthcare professionals in a variety of clinical and non-clinical settings, including, but not limited to, university-based medical centers, private hospitals, private practice, and industry settings. The instruction in clinical genetics, counseling, and communication skills required to carry out the professional responsibilities described in this statement is provided in graduate training programs accredited by the American Board of Genetic Counseling (ABGC)² or the equivalent, as well as through professional experience and continuing education courses.

The responsibilities of a genetic counselor are threefold: (i) to provide expertise in clinical genetics; (ii) to counsel and communicate with patients on matters of clinical genetics; and (iii) to provide genetic counseling services in accordance with professional ethics and values. Specifically:

Section I: Clinical Genetics

1. Explain the nature of genetics evaluation to clients. Obtain and review medical and family histories, based on the referral indication, and document the family history using standard pedigree nomenclature.
2. Identify additional client and family medical information relevant to risk assessment and consideration of differential diagnoses, and assist in obtaining such information.
3. Research and summarize pertinent data from the published literature, databases, and other professional resources, as necessary for each client.
4. Synthesize client and family medical information and data obtained from additional research as the basis for risk assessment, differential diagnosis, genetic testing options, reproductive options, follow-up recommendations, and case management.
5. Assess the risk of occurrence or recurrence of a genetic condition or birth defect, using a variety of techniques, including knowledge of inheritance patterns, epidemiologic data, quantitative genetics principles, statistical models, and evaluation of clinical information, as applicable.

6. Explain to clients, verbally and/or in writing, medical information regarding the diagnosis or potential occurrence of a genetic condition or birth defect, including etiology, natural history, inheritance, disease management and potential treatment options.
7. Discuss available options and delineate the risks, benefits and limitations of appropriate tests and clinical assessments. Order tests and perform clinical assessments in accordance with local, state and federal regulations.
8. Document case information clearly and concisely in the medical record and in correspondence to referring physicians, and discuss case information with other members of the healthcare team, as necessary.
9. Assist clients in evaluating the risks, benefits and limitations of participation in research, and facilitate the informed consent process.
10. Identify and access local, regional, and national resources such as support groups and ancillary services; discuss the availability of such resources with clients; and provide referrals, as necessary.
11. Plan, organize and conduct public and professional education programs on medical genetics, patient care and genetic counseling issues.

Section II: Counseling and Communication

1. Develop a genetic counseling agenda with the client or clients that includes identification and negotiation of client/counselor priorities and expectations.
2. Identify individual client and family experiences, behaviors, emotions, perceptions, values, and cultural and religious beliefs in order to facilitate individualized decision making and coping.
3. Assess client understanding and response to medical information and its implications, and educate client appropriately.
4. Utilize appropriate interviewing techniques and empathic listening to establish rapport, identify major concerns and engage clients in an exploration of their responses to the implications of the findings, genetic risks, and available options/interventions.
5. Identify the client's psychological needs, stressors and sources of emotional and psychological support in order to determine appropriate interventions and/or referrals.

6. Promote client-specific decision making in an unbiased non-coercive manner that respects the client's culture, language, traditions, lifestyle, religious beliefs and values.
7. Use knowledge of psychological structure to apply client-centered techniques and family systems theory to facilitate adjustment to the occurrence or risk of occurrence of a congenital or genetic disorder.

Section III: Professional Ethics and Values

1. Recognize and respond to ethical and moral dilemmas arising in practice, identify factors that promote or hinder client autonomy, and understand issues surrounding privacy, informed consent, confidentiality, real or potential discrimination and potential conflicts of interest.
2. Advocate for clients, which includes understanding client needs and perceptions, representing their interests in accessing services, and eliciting responses from the medical and social service systems as well as the community at large.
3. Recognize personal limitations in knowledge and/or capabilities and seek consultation or appropriately refer clients to other providers.
4. Maintain professional growth, which includes acquiring relevant information required for a given situation, keeping abreast of current standards of practice as well as societal developments, and seeking out or establishing mechanisms for peer support.
5. Respect a client's right to confidentiality, being mindful of local, state and federal regulations governing release of personal health information.

This Scope of Practice statement was approved in June 2007 by the National Society of Genetic Counselors (NSGC) - the leading voice, advocate and authority for the genetic counseling profession. It is not intended to replace the judgment of an individual genetic counselor with respect to particular clients or special clinical situations and cannot be considered inclusive of all practices or exclusive of other practices reasonably directed at obtaining the same results. In addition, the practice of genetic counseling is subject to regulation by federal, state and local governments. In a subject jurisdiction, any such regulations will take precedence over this statement. NSGC expressly disclaims any warranties or guarantees, express or implied, and shall not be liable for damages of any kind, in connection with the information set forth in this Scope of Practice statement or for reliance on its contents.

Genetic counseling is a dynamic profession, which undergoes rapid change with the discovery of new genetic information and the development of new genetic tests and treatment options. Thus, NSGC will periodically review and, where appropriate, revise this statement as necessary for consistency with current practice information.

References:

1. NSGC Definition of Genetic Counseling. Journal of Genetic Counseling April 2006; 77-82
2. American board of Genetic Counseling website; www.abgc.net

For additional information, please contact the National Society of Genetic Counselors.