

National Association of Social Workers

NASW Standards for Integrating Genetics into Social Work Practice

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Introduction

Current and emerging advances in the science of genetics provide significant promise for enhanced health and well-being and an opportunity for social workers to make a major contribution. As rapid discoveries in *genetics* (the study of single genes and their effects) and *genomics* (the study of the functions and interaction of all the genes in the genome) continue to identify genetic components of common diseases such as Alzheimer's, diabetes, cancer, heart disease, mental illness, and even behavioral characteristics, virtually everyone will be affected, our clients as well as ourselves (Guttmacher & Collins, 2002). Knowledge of the genetic makeup of oneself or a family member may present significant dilemmas and may lead to a serious consideration of alternative life plans. A genetic test can alert people to advanced detection and management of some disorders, but currently the ability to test for a genetic disorder often exceeds science's ability to prevent or cure genetic disease. The social worker's role in encouraging clients to become their own advocates in bringing genetic issues to the forefront of quality health care is being defined in part by the completion of the Human Genome Project (HGP), the international effort to map and sequence all the genes in the human body.

A social worker is often the first to provide psychosocial services to individuals and families with genetic disorders. Therefore, it is imperative that social workers become more aware of the ethical, legal and psychosocial implications of a genetic diagnosis, genetic testing and genetic research in order to empower individuals and families to speak out for their rights as public citizens. In addition, the profession must continue to be active in shaping public policy as well as organizational policy as it relates to genetics and service delivery. Without specialized training, it is inappropriate for social workers to assume the role of genetic counselors, but they have important contributions to make within the social work scope of practice. Social workers can take an active part in ensuring that their clients are protected against genetic discrimination in areas such as health and life insurance, employment, and adoption. There are increasing

opportunities for professional development of social workers in the field of genetics, and social workers should take the initiative to seek out those resources.

As critical issues are identified in the field of genetics, such as the benefits and risks of gene therapy, stem cell research, reproductive technology, and tissue cloning, social workers need to become more informed and sensitive to related ethical, legal, and psychosocial considerations to be helpful to their clients. It is also important that they become knowledgeable about genetic resources in the community.

The ongoing knowledge explosion in genetics and its positive and challenging sequelae present considerable opportunities for the social work profession. Increasingly social workers will be called on to develop as well as confront emerging policies related to genetic testing and treatment.

The National Association of Social Workers (NASW) recognizes the need to integrate knowledge of genetics into social work practice in the context of the NASW *Code of Ethics* (1999). The standards that are delineated in this brochure represent a foundation for introducing genetics into social work practice

History of Social Workers and Genetics

For more than 40 years, social work as a profession has recognized the importance of genetic disorders in relation to social work practice and education. The Human Genome Education Model (HuGEM) project, funded by the National Institutes of Health and co-chaired by two social workers, offered workshops and training programs in genetics for social workers and other disciplines across the country from 1997 to 2001 (Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000). NASW was an active participant in this project, which served as a catalyst for increased involvement in the field. The National Coalition of Health Professionals in Genetic Education (NCHPEG) was formed in 1996 and included two social workers representing both NASW and the Council on Social Work Education (CSWE) on its steering committee. NCHPEG has developed core competencies in genetics for all health-care professionals; these

competencies have been useful in the development of these practice standards for social workers (Jenkins et al., 2001).

In addition to the efforts to improve social work education in genetics, the social work practice community has worked to clarify the social work role in genetics. An *NASW Social Work Practice Update* in 1998 defined the role of social workers in genetics, emphasizing practice, policy, and ethical issues (Taylor-Brown & Johnson, 1998). The NASW policy statement on Genetics provided a framework all social workers could use to understand ethical and practical issues in genetic testing and research (NASW, 2003). In these NASW documents, it was made clear that social workers in all fields need to understand the ethical and practical issues involved with genetic testing. These include informed consent, confidentiality, self-determination, equal access, and the implications of knowing one's genetic make-up. The *Practice Update* emphasized the importance of social workers assisting individuals and their families in weighing the positive and potentially deleterious aspects of genetic testing and treatment options. The Policy Statement included a commitment by NASW to continue work to establish the social work profession as a leader in the field of genetics, to support the development of programs, training, and information that provide social workers with current genetic information for use with clients, and to support policies that provide protection for clients from employment and insurance discrimination.

Goals of the Standards

These standards address genetics as an expanding field of knowledge for social workers and emphasize the need for clarification of, understanding of, and education about this specialized area.

The standards are designed to enhance social workers' awareness of the skills, knowledge, values, methods, and sensitivity needed to work effectively with clients, families, health care providers, and the community and to increase their understanding of the impact that the field of genetics has, and will have, on them.

It is hoped that these standards will lead to the development of clear guidelines, goals, and objectives for expanding current and future areas of social work practice, research, and policy in genetics.

The specific objectives of the standards are

- ◆ to inform social workers about genetics as an expanding field of social work knowledge
- ◆ to improve the quality of social work services provided to clients with genetic disorders
- ◆ to provide a basis for the development of continuing education materials and programs in genetics
- ◆ to ensure that social work services to clients with genetic disorders are guided by the NASW *Code of Ethics*
- ◆ to advocate for clients' right to self-determination, confidentiality, access to genetic services and nondiscrimination
- ◆ to encourage social workers to participate in the formulation and refinement of public policy (at the state and federal levels) relevant to genetic research, services, and treatment of populations with genetically identified predispositions or conditions.

Standard 1: Ethics and Values

When integrating genetics and social work practice, social workers shall function in accordance with ethical principles and standards of the profession as articulated in the *NASW Code of Ethics* (NASW, 1999).

Interpretation

Social workers can make a significant contribution to the field of genetics by advancing a humane and ethical approach. Among the current ethical issues of relevance to the social work profession are

- ◆ equitable access to genetic services, including testing and treatment and financial coverage for these procedures
- ◆ privacy and confidentiality of individual genetic information, particularly in relation to the insurance industry and employers
- ◆ self-determination, including allowing the client to select or refuse genetic testing and treatment in a noncoercive, unbiased manner; allowing the client to exercise the right to know or to refuse to know genetic information
- ◆ informed consent, including protecting the right of the client to make decisions with regard to genetic testing and research based on a clear understanding of the risks and benefits
- ◆ voluntary genetic testing and treatment
- ◆ appropriate authority for genetic decision making on behalf of children and impaired adults
- ◆ protection of the rights of those living with genetically determined conditions.

With its historic commitment to serving and empowering populations at risk and promoting human rights and social justice, social work is well suited to address the ethical challenges that arise from new genetic knowledge. The *NASW Code of Ethics* (1999) provides a philosophical framework for ethical social work practice and a set of ethical standards intended to define acceptable professional behavior. Cultural competence is highlighted and practitioners are

enjoined to provide culturally sensitive services. Although the genetic make-up of all individuals across the spectrum of racial and ethnic groups is remarkably similar, the NASW Code acknowledges that members of different cultures have unique norms, traditions, and coping strategies that must be understood and respected. The client's right to privacy and confidentiality, self-determination, nondiscrimination, and social justice are clearly articulated in the Code. Genetic services should be interdisciplinary to achieve a holistic approach to client care. In this context, these standards address mutually respectful relationships among colleagues. The Code also acknowledges the complexity of ethical dilemmas, which defy simple answers. The Code suggests that the resolution of seemingly contrary mandates is best approached through a reasoned, systematic process that incorporates ethical theory and appropriate peer and interdisciplinary consultation and supervision.

Standard 2: Genetics Knowledge

Social workers shall acquire a basic understanding about genetics as a science and a field of study, including its biological, psychosocial, ethical, and legal aspects.

Interpretation

Advances in the scientific understanding of the human genome leads to better comprehension of diseases, both common and rare, and ultimately leads to better diagnosis and treatment. Because of the rapid increase in genetic knowledge and because most social workers do not have a background in genetics, they need to gain a basic understanding of predisposition to common illness and inherited disease patterns. Social workers must continually update their understanding as new knowledge becomes available.

Social workers need to become familiar with general terminology used in human genetics and basic patterns of biological inheritance and with the role of genetic factors in maintaining health and preventing disease. Because many diseases are now understood to involve a combination of causative factors, including but not limited to genetics, social workers need to understand how social, behavioral, cultural, economic, and environmental factors interact with biological factors to influence health. It is important to include a relevant medical history in social work assessments in working with families. A family history is crucial in determining a genetic diagnosis and in predicting how various family members might be affected in the future. Social workers therefore have an important role to play in this area, particularly in knowing when to refer their families to genetic counselors and genetic clinics.

Although new information on genetics has increased our understanding of the etiology of physical and mental illness, prevention and treatment of genetic disorders are very limited. This creates difficult dilemmas for people who are now in a position to decide whether to get tested themselves or to have their children tested. People who are at risk of genetic disorders will have increased options to use the new information to guide their reproductive behavior. However, many of the possibilities (for example, prenatal diagnosis, elective termination of abnormal

pregnancies, in-utero treatments, in-vitro fertilization, trait selection combined with selective implantation) raise serious moral questions.

As the genetic basis of common diseases becomes better known, it is especially important for social workers to become knowledgeable about indications for genetic testing and referral resources for such testing. In cases where genetic testing is available, social workers need to understand the potential benefits and risks of genetic knowledge to individuals, families, and communities. Social workers involved in the adoption process need to be aware of the impact of genetic testing on all parties, and place the best interests of the newborns and children first. Psychosocial reactions to genetic testing, cognitive responses, and coping strategies are important areas of knowledge for social workers, as are family issues.

A genetic test may provide people with information that can inform both their reproductive decisions and health behaviors. Because environment affects genetic expression, a genetic test may also alert people to a need to change their physical and social environments—something social workers are particularly skilled in assisting people to do.

Genetic testing has an uneven history in the United States, and social workers need to be familiar with this and have an understanding of how genetic information can be beneficial or misused. Social workers should understand and advocate for legislation that prohibits genetic discrimination and protects against inappropriate disclosure. Social workers working with clients should make efforts to keep current with legislative and legal developments through continuing education and in-service training.

Social workers need to be able to locate genetic resources in their communities and elsewhere. They need adequate understanding of genetic counseling and how it differs from other types of counseling. This knowledge is helpful in explaining to clients what to expect from genetics professionals and what to expect from social workers. They need to know when referrals are needed and how insurance coverage applies to genetic services.

Standard 3: Practice Skills in Working with Individuals, Families, Groups, and Communities

Social workers shall use appropriate practice theories, skills, and interventions that reflect their understanding of genetic factors in their work with individuals, families, groups, and communities.

Interpretation

Basic social work skills can be used to provide genetic services to individuals, families, groups, and communities. A professional commitment to continuing education in genetics is necessary for the integration of current and emerging genetic information and technology into appropriate social work settings. The social workers' biopsychosocial perspective is ideal for their role as liaisons between health professionals and clients, client advocates, and providers of psychosocial support services. Social work interventions can facilitate the identification of individuals in need of medical referral or genetic counseling services, and should include initiating referrals. The social worker should serve as an advocate for these clients, assisting individuals and families in adjusting to chronic health conditions, creating and maintaining appropriate self-help groups, resolving bereavement issues, and taking action at the community level regarding genetic privacy and potential discrimination.

More specifically, social workers should develop skills to

- ◆ gather relevant genetic family history information, including a multigenerational family history that includes parents, children, siblings, grandparents, aunts/uncles, cousins
- ◆ identify clients who might benefit from a referral for genetic services
- ◆ properly communicate to clients the purpose of genetic services and the role of various genetic professionals
- ◆ provide culturally sensitive services to clients with or at risk of genetic conditions
- ◆ seek assistance from and refer to appropriate genetics experts and peer support resources
- ◆ explore with clients the possible range of emotional effects they and family members may experience as a result of receiving or refusing genetic information

- ◆ assist clients and their families in the genetic decision-making process, and in adapting to genetic information throughout the life cycle
- ◆ discuss costs of genetic services and insurance benefits
- ◆ discuss potential risks of discrimination in insurance, employment, adoption, and other areas
- ◆ safeguard privacy and confidentiality of genetic information of clients to the extent possible
- ◆ facilitate the creation and maintenance of support resources for genetic service clients
- ◆ obtain current genetic information from reliable sources, for self, clients, and colleagues
- ◆ educate clients, professionals and the community about policy issues regarding genetics
- ◆ advocate for client-focused public policy in genetics.
- ◆ assist clients in the understanding of the limitations and benefits of participating in genetics research and the importance of informed consent.

Standard 4: Client/Practitioner Collaborative Practice Model

Social workers shall be able to work with their clients with genetic concerns in a partnership that includes mutual respect, shared information, and effective communication.

Interpretation

Individuals and families who have genetic concerns and those serving them have a shared commitment to quality services for everyone. Clients have expert knowledge of themselves and their family situations. Social workers should build partnerships with clients who are affected by genetic diagnoses to create new genetic resources, fight genetic discrimination, and ensure that the needs of individuals and families with genetic concerns are met.

Social workers can be helpful to individuals and families in understanding the information they receive about their genetic makeup. Clients need to have a role in the collaborative team when choices regarding health care and other genetic services are being considered. Social workers should be aware of the psychological dynamics that individuals and families experience when making genetic decisions. In addition, social workers and their clients with genetic conditions should pool their knowledge, skills, and experience to advocate for needed programs and services.

Standard 5: Interdisciplinary Practice

Social workers shall participate in multidisciplinary teams that deliver comprehensive genetics services.

Interpretation

The complexity of genetic conditions requires a holistic approach to intervention. Individuals and families with genetic disorders, or at risk of them, need to receive services from a variety of health professionals working collaboratively to ensure optimal benefit. Multidisciplinary teamwork is central to the new, dynamic science of genetics (Weiss, Bernhardt, & Paul, 1984). More effective services are provided when an interdisciplinary team shares its expertise with individuals and families with genetic disorders.

By virtue of their education and training, social work professionals are well suited to working as part of a multidisciplinary team. Social workers have expertise in identifying and coordinating services and in bridging gaps in professional communication among service providers.

A common goal for all disciplines is to provide quality services to the population of affected persons and their families. In particular, all disciplines must be attuned to the emotional and social needs of individuals with genetic conditions. Healthcare professionals such as social workers, psychiatrists, psychologists, and nurses who provide psychosocial services to individuals and families can include genetic issues in these services. Other health professionals such as audiologists, speech and language pathologists, nutritionists, occupational therapists, physical therapists, and special educators also provide important services to people with genetic disorders. They have much to learn from one another in helping their clients or patients who must cope with these disorders.

Social workers, with a team approach, can establish bridges between clients and health professionals such as genetic counselors, medical geneticists, and primary care physicians. In addition, the support group/professional partnership is essential in empowering individuals and families living with genetic disorders.

Standard 6: Self-Awareness

Social workers shall have and continue to develop an understanding of their own personal, cultural and spiritual values and beliefs pertaining to genetics and genetic therapies.

Interpretation

Genetic knowledge and practices may conflict with basic beliefs, not only in clients, but in social workers themselves. To be able to effectively assist clients, social workers must continually examine their own backgrounds and identify their assumptions, values and beliefs related to human reproduction, medical intervention and the value of life with major disabilities. Social workers must recognize the fact that clients come from a wide variety of religious and cultural backgrounds that may differ from those of the social worker.

Becoming a self-aware and self-reflective practitioner involves the examination of one's own bias about groups with views different from one's own. Social workers need to work to develop an understanding of different views, and to avoid judging clients with different values. They also must understand how a practitioner can subtly influence clients with different beliefs through choice of words and nonverbal expressions and reactions and must learn the skills to avoid doing so in their practice. There may be situations in which social workers will find themselves unable to empathize or remain objective. Self-awareness means taking responsibility for identifying such situations and working on one's issues so that they do not interfere with the client's decision-making. In instances where the social worker is unable to accomplish this, referral should be made to a social worker who can be neutral while assisting clients in this highly sensitive work.

Standard 7: Genetics and Cross-Cultural Knowledge

Social workers shall have and continue to develop specialized knowledge and understanding about the history, traditions, values, and family systems of client groups as they relate to genetics.

Interpretation

Social workers need to possess specialized knowledge regarding the influences of their clients' ethnicity, culture, values, religious and health beliefs, and economic situations to understand their client's use of genetic information and services. In providing clinical services, social workers can obtain the socio-cultural knowledge through exploration with the client, starting with a family history, or health concern. The social worker will need to assess the meaning the client is placing on this concern. This process of cultural exploration is needed to assist in decision making regarding the pursuit of genetic information and later the results of that decision on the individual, the family, the community and the wider social context. NASW has developed *NASW Standards for Cultural Competence in Social Work Practice* that establish guidelines for practice (NASW, 2001).

There are many sociocultural barriers to genetic services. Social workers should use and promote the use of appropriate language and literacy levels when discussing genetic information with clients and their families. When taking a genetic family history, they should be culturally sensitive and aware of language and underlying emotional content. The social worker should be alert to cultural factors in working with individuals and families regarding their understanding of genetic information and issues in genetic decision making. As a client advocate, the social worker must address genetic privacy and confidentiality of genetic information with an awareness of possible cultural meaning and social stigma for an individual or a group.

In summary, social workers may assist in overcoming cultural barriers to genetic services by

- ◆ using and promoting the use of appropriate language and literacy levels when communicating with clients and their families in regard to genetic information
- ◆ being culturally sensitive in obtaining a genetic family history
- ◆ being aware of cultural factors in working with individuals and families regarding the genetic decision making process and in adapting to genetic information
- ◆ addressing genetic privacy and confidentiality of genetic information with an awareness of possible cultural meaning and social stigma for an individual or a group
- ◆ advocating for cultural competence in service delivery and throughout the health system

Standard 8: Research

Social workers shall contribute to, support, and be cognizant of the development of research-based and practice-relevant knowledge of the psychosocial, cultural, economic, and ethical implications of genetics on individuals, families and society.

Interpretation

Much remains to be learned about how to promote the well-being of individuals, families and society in the context of the genetic revolution. Research is needed on how individuals and families react to learning about their genetic risk status, how they make decisions based on that knowledge, and how society can ensure that genetic information is used for the common good. Research can inform our understanding of how genetic information may differentially affect the diverse cultural and ethnic groups within our society, and how to be culturally sensitive to these differences. The *NASW Code of Ethics* (NASW, 1999) states that social workers should “contribute to the knowledge base” of the profession [5.01 (d)], and “promote and facilitate evaluation and research to contribute to the development of knowledge” [5.02 (b)]. Moreover, the Code states that “when generally recognized standards do not exist with respect to an emerging area of practice, social workers should...take responsible steps (including appropriate education, research) to ensure the competence of their work and to protect clients from harm” [1.04 (c)].

Social work’s “person-in-environment” perspective can make a unique contribution to the understanding of the impact of genetic information on our society (Germain & Gitterman 1995). Social workers are ideally suited to observe the impact of genetic information on individuals, families, and society; draw preliminary generalizations; and form theories that may be tested in research studies to enhance social work practice. They can initiate surveys among client populations, and document potential problems created by genetic testing, such as discrimination in insurance and employment.

Social work research must be guided by basic ethical and cultural principles, as defined by the *Code of Ethics of the National Association of Social Workers* (1999). Promotion of the well-being of the client is the primary responsibility of the social worker. Informed consent, the equitable selection of subjects, privacy and confidentiality, the right to withdraw from studies, and avoidance of harm are among the standards that are essential for ethical research studies (National Bioethics Advisory Commission, 2002). The consequences of research must be considered, and appropriate institutional review boards consulted in the early stages of project development. Social workers must also keep current with emerging research by other professionals, and should collaborate in multi-disciplinary research with other interested professions, such as medicine, nursing, genetic counseling, psychology, and law.

Standard 9: Advocacy

Social workers shall safeguard the privacy and confidentiality of genetic information of their clients and advocate for and with clients when appropriate to ensure fair social policies and access to quality genetic services.

Interpretation

Social workers are keenly aware of the importance of maintaining their clients' privacy with regard to genetic information, as well as the potential for discrimination based on that information and the need for social advocacy and social action to better empower clients and communities.

To protect clients, social workers must be aware that there are limitations to the confidentiality of genetic test information. Insurance companies, employers, the criminal justice system, and other government agencies have enormous financial incentives to gain access to people's genetic information. Federal and state policies may not adequately protect people from the use of genetic tests for purposes of discrimination in underwriting and employment. Of particular concern to social workers is the potential for labeling individuals and withholding services from those with genetic conditions.

The right to confidentiality extends to both the decision whether to be tested and the decision of who is allowed access to the test results. Social workers should inform clients about the possible disclosure of confidential information and the potential consequences before the disclosure is made.

As public policy is developed to define access and funding for genetic services, social workers must be active participants to the process. Social workers should also keep current with federal and state legislation pertaining to genetics and encourage their clients to do the same.

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