Genetics

A revision of an existing statement

Second Round Policy Panel Version

BACKGROUND

With the completion of the human genome sequence in 2003, it is thought that all disease, with the possible exception of trauma, is a result of the interaction of one’s genes and the environment. Emerging advances in the science of genetics (the study of single genes and their effects) and genomics (the study of the functions and interaction of all the genes in the human body) not only identify thousands of rare disorders, but also define genetic components of common diseases such as Alzheimer’s, cancer, mental illness, diabetes, heart disease, and autism (Guttmacher & Collins, 2002). As predictive genetic testing becomes more available for some of these common diseases, it is imperative that social workers begin incorporating genetic thinking and genetic principles in their practices. Understanding the psychosocial and ethical implications of genetic testing is important for all social workers, no matter where they are practicing. Social workers can take an active part in ensuring that clients are protected against genetic discrimination by insurance companies, employers, schools, adoption agencies, and the government.

As social workers, we must respect genetic diversity and the uniqueness of the individual, regardless of his or her genetic makeup (Weiss, 2004), including the ability to recognize the difference between components of genetic make-up and learned traits. It is important that social workers recognize how vital their role is in helping clients come to
terms with being at risk of a genetic condition or facing the uncertainty of a genetic
diagnosis in the family.

Genetic research studies each individual’s unique combination of approximately
30,000 genes located on the 23 pairs of chromosomes found in each human cell. Each
gene or combination of genes in interaction with the environment is responsible for an
individual’s particular traits and disorders. For example, one’s hair color, gender, and eye
color are determined by genes. Genes also play an important role in health, mental health,
and to a yet unknown degree, behavior. One interesting finding of the Human Genome
Project was that all individuals are 99.9 percent the same with respect to their DNA
sequence. Pharmacogenomics is a recent development of tailoring of drugs for patients
on an individual basis. The National Human Genome Research Institute supports the
dissemination of genome information to the public and health professionals.

Genetics is not a new science. Gregor Mendel discovered the laws of heredity in
the 1800s (Bishop & Waldholz, 1990); nor is genetics a new field for social workers. For
the past 40 years, social workers have been providing genetic services and writing about
In recent years, the social work profession has taken a more active role in the arena of
genetics and genomics. 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). The National Coalition of Health Professional Education in Genetics (NCHPEG)
was formed in 1996 and included two social workers representing both NASW and the
Council on Social Work Education on its steering committee. NASW developed *Standards for Integrating Genetics in Social Work Practice* in 2003 and an online continuing education course titled *Understanding Genetics: The Social Worker’s Role* in 2007. What is new is the genetic information now available and its impact on both clients and practitioners. An array of issues related to genetics arises at all levels of social work practice: from clinical practice to family practice to policy making. Clients face both benefits and risks now and in the future from genetic research.

Genetics is an expanding field of practice for social workers. Science and technology are quickly moving toward a time in which most human maladies can be identified and, once identified, treated, cured, or even prevented. Yet this seemingly liberating possibility for knowledge is fraught with potential for harm to the people social workers serve. Issues of informed consent and confidentiality arise, as do those of discrimination, self-determination, and the immediate benefits of genetic test results.

Unfortunately, in most cases results of genetic tests are not clear-cut. One-to-one gene-disorder relationships are rare. In fact, most disorders are the combination of more than one gene and environmental factors. Predictive or pre-symptomatic tests can identify individuals at risk of getting a disease, such as certain types of cancer, before the onset of symptoms. However, although a particular gene combination may be identified with certainty, these tests cannot predict whether the disorder will ever be manifested, with the possible exception of identifying a late-onset condition, such as Huntington disease. For example, the genes linked to breast cancer, BRCA1 and BRCA2, can be identified by a predictive test. These genes are found in only 5 percent of the population, and even if the
gene is found, 20 percent of individuals with a positive test will never get that type of breast cancer. On the other hand, even though the gene is not present, one in nine women (11 percent) will have breast cancer in their lifetime (Geller et al., 1997). Although genetic testing is becoming an integral part of health care, often the availability of the test is not followed by developed treatments. Advantages of genetic testing, such as facilitating choices about family planning, preventive lifestyle measures, or increased surveillance must be balanced against the risk of genetic discrimination. The advent of genetic testing, now available for about 1,000 diseases, raises many questions about how an individual’s genetic information can be used, and the threat of discrimination hinders both genetic research and clinical practice (Williams, 2006). Direct-to-consumer marketing of genetic testing increases the risk that violations of genetic privacy will follow and eliminates face-to-face counseling (Roche & Annas, 2006).

To make an informed decision to have a genetic test, a client has to have access to current, accurate information regarding benefits and risks of genetic testing to the client and to family members. Information includes limits of protection of confidentiality under federal and state law; strengths and limitations of the test itself; availability of prevention, treatment, and cure; and potential risks of stigmatization, discrimination, and psychological distress, including risk to intra-family relationships. Social workers may make referrals to other professionals, such as genetic counselors, to maximize the amount of knowledge available to the client for purposes of deciding whether to be tested.

People seek genetic testing usually for one of four reasons: (1) for diagnosis to determine if they currently have a particular disorder; (2) for asymptomatic testing to determine if they have a particular genetic disorder that will manifest itself in the future;
(3) for prenatal planning to determine if they carry the gene or genes for a particular disorder that may affect future generations; or (4) to determine whether they are susceptible to a particular disorder in the future. The results of these tests carry unique psychological implications for individuals and their families (Fanos, 1997; Fanos & Johnson, 1995).

Once educated about whether treatment for a particular disease exists, each person must weigh the options based on individual benefits and risks. In cases where a treatment or cure is possible, the options seem clear. However, if the test can only establish susceptibility, if there is no treatment or cure, or both, then for some the risks of discrimination and psychological stress may outweigh the benefits. Social workers should ensure that the client has access to all of the information necessary to make the decision to be tested and that the decision reflects the self-determination of the client.

Minors often do not have the opportunity to make decisions for themselves about whether to be tested. The Task Force on Genetic Testing, the advisory committee of the National Human Genetic Research Institute (1997) stated: Genetic testing of children for adult onset disease should not be undertaken unless direct medical benefit will accrue to the child and his benefit would be lost by waiting until the child has reached adulthood. Many of the issues regarding children are still formative, including those relevant to testing minors for decisions to be made by adoptive parents, adopted children having the right to know their biological parents’ genetic makeup, and children conceived by a gamete donor having a right to their donor’s genetic test (Fanos, 1997; Wertz, Fanos, & Reilly, 1994). Research is continuing with regard to genetic determinants for psychiatric disorders, addictions, and social behavior, and some progress
has been made. However, this raises the question of potential treatment when needed versus labeling and incarceration.

**ISSUE STATEMENT**

Fear of genetic discrimination could limit participation in research, willingness to have genetic testing, and genetic screening (Hall McEwen et al, 2005). At least three possibilities for discrimination arise regarding genetic testing. One is societal: People may be stigmatized or labeled if they are found to be susceptible, for example, to cancer or have a potential disability. Another is financial: An employer could turn down a client for employment because the client may cost the company too much money in insurance costs related to the clients genetic test results, or the client could be denied insurance coverage for the treatment of the disease. A third is access to potentially helpful genetic testing for members of minority groups and poor people (Hudson, Rothenberg, Andrews, Kahn, & Collins, 1995; Rothenberg et al., 1997, Wertz, 1998). Although many states have laws that provide protections from using genetic information in a discriminatory manner, the need for federal legislation has not been met (Smith, 2004).

Social work practice in the context of genetic testing is guided by the *NASW Code of Ethics* (NASW, 2000) and the *NASW Standards for Integrating Genetics in Social Work Practice* (2003). Although several ethical standards apply to genetic practice, three are especially relevant: informed consent, confidentiality and protection from discrimination. Ability to gain knowledge of one’s genetic makeup or a family member’s genetic makeup carries significant risks. A genetic test may alert people about the
prevention, treatment, and cure of some disorders, but currently the ability to test for a genetic disorder often exceeds science’s ability to prevent, treat, and cure genetic disease (Taylor-Brown & Johnson, 1998). In most cases people are tested for diseases for which there is no known treatment or cure. Clients thus face significant psychological risks when learning of traits or disorders as a result of genetic testing (Lapham, Kozma, & Weiss, 1996). They also risk potential discrimination by insurance companies, employers, and society for traits or disorders. In addition, there are financial incentives for private companies to patent and sell genetic tests, even though their use is of limited benefit to some clients. Consequently, the requirement for comprehensive informed consent cannot be overstated.

To protect clients, social workers must know of the limitations of confidentiality to genetic test information. There are enormous financial incentives for insurance companies, employers, the criminal justice system, and other government agencies to have access to people’s genetic information, and never before have these groups had the ability to know the potential for future health problems (Andrews, Fullarton, Holtzman, & Motulsky, 1994). Although most states have some protections against the discriminatory use of genetic information by health insurers and employers, the laws differ widely and there is no national standard at present. Current federal and state policies do not protect the use of genetic tests for purposes of discrimination in underwriting and employment (Hudson, 2007). Of particular concern to social workers is the potential for labeling individuals and withholding services for people with mental health, mental retardation, and behavioral disorders such as alcoholism, drug use, and even anger. Testing of minors is also a relevant issue here. The right to confidentiality
extends to both the decision to be tested and the decision of who is allowed access to the
test results. Ethical Standard 1.07(d), Privacy and Confidentiality, is applicable: “Social
workers should inform clients, to the extent possible, about the disclosure of confidential
information and the potential consequences, when feasible before the disclosure is made”
(NASW, 2000, p. 10). Applied to genetic testing, this means that social workers should
inform clients of the potential limitations to confidential test results and the
consequences.

Two other significant issues involve competence in providing services alone and
in teams and advocacy. If social workers are to provide services related to genetic testing,
they must be competent in the content and services they provide, and they must remain
competent as the field emerges (Ethical Standards 1.04, Competence, and 1.05, Cultural
Competence). In light of the plethora of issues, the decision to be tested must be the
client’s, without coercion from insurance companies or family members and based on
informed consent (Ethical Standard 1.02, Self-Determination). Because of the complexity
of providing genetics services, social workers often practice with multidisciplinary teams.
Ethical Standard 2.03, Interdisciplinary Collaboration, defines the social worker’s role
and ethical responsibilities to the client in relation to interdisciplinary collaboration.
Finally, for social workers to help protect clients’ and society’s interest in the benefits of
genetic testing, social workers’ advocacy role in public policy is essential (Ethical
Standard 6.04, Social and Political Action). The role of social workers as advocates in the
field of genetics is defined in the *NASW Standards for Integrating Genetics in Social
Work Practice*. Standard 9 discusses the need to advocate on behalf of clients to ensure
fair social policies and access to quality genetic services (NASW, 2003). As more
attention is paid to benefits and risks of stem cell research, reproductive technology, tissue cloning, and gene therapy, social workers will be called on to develop and confront emerging policies related to genetic testing and treatment.

**POLICY STATEMENT**

**The Profession**

- NASW maintains a commitment to continue work to establish the social work profession as a leader in the field of genetics.
- NASW encourages social workers to educate themselves through formal and informal educational opportunities as well as through reading professional journals and chapter materials regarding current issues in genetics.
- NASW recommends that social workers become familiar with the *Standards of Integrating Genetics in Social Work Practice*.
- NASW supports the development of programs, training, and information that provide social workers with current genetics information for use with clients.

**State and Federal Policies**

- NASW opposes genetics policies that interfere with an individual’s right to choose to be tested or not.
- NASW opposes genetics testing policies that are discriminatory in terms of access to genetics services.
- NASW opposes policies that coerce clients into reproductive decisions as a result of genetics test results that they would not otherwise make.
NASW opposes the use of genetic research to alter populations of people and to remove certain traits deemed by society as “unfit.”

NASW opposes patenting naturally occurring human genetic structure.

NASW supports policies that protect the client’s ownership of his or her own genetic information and that protect the confidentiality of, access to, and use of an individual’s genetic tests.

NASW supports policies that provide protection for clients from discrimination in employment and by insurance companies or protection from efforts to limit freedom of education or other civil rights based on a genetic test.

NASW advocates for client-focused public policy for genetic testing, so that all clients may receive the benefits of genetic testing.

NASW supports policies that protect the rights of minors to be tested only when there is a present and current benefit to the child that would be lost if the test is not done until the child becomes an adult.

NASW supports responsible stem cell research.

**Practice**

NASW encourages interdisciplinary research between social work and other disciplines to determine the impact of genetic testing on clients.

NASW encourages ongoing collaborative research between social work practitioners and educators to determine the impact of genetic testing on clients.

NASW supports the development of psychosocial support services for clients with genetic disorders.
NASW encourages all social workers to take families histories that include medical intergenerational information whenever possible.

NASW supports client self-determination regarding genetic testing decisions and encourages social workers to educate clients about the benefits and risks of genetic testing and to provide such education in a value-free, nondirective way.

REFERENCES


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