WHAT SOCIAL WORKERS NEED TO KNOW ABOUT GENETICS

Joan O. Weiss, ACSW, LICSW

"Why should social workers know anything about genetics? After all, we are interested in people, not science…"

Social workers do not have to become experts in genetics, but they will need to start incorporating genetic thinking and genetic principles in their practices. Social workers should be able to include genetic information in family histories; understand basic genetics terminology and patterns of inheritance; know how and when to make referrals to genetic counselors and genetic clinics; and understand the psychological, ethical, and social implications of genetic services. The rapid advances in science and medicine resulting from the completion of the Human Genome Project in 2003 make it imperative that social workers have enough background in genetics to help their clients better understand and cope with the impact of genetic information on themselves and their families (Weiss, 2002).

Each day, social workers see clients who have genetic conditions or who are at risk for them. These clients must make genetic decisions and choices that may affect them and their family members; increasingly, this will lead to seeking the help of social workers. Therefore, it is important that social workers become informed about the ethical and psychosocial implications of genetic testing and genetic research. Individuals attempting to adjust to a genetic diagnosis, grappling with whether or not to take genetic tests, or feeling damaged by being carriers of altered genes or passing on a genetic disorder to their offspring will continue to need psychosocial counseling.

In the past, genetics has dealt with rare, single-gene disorders or See Genetics, Page 17
THE PSYCHOLOGICAL IMPACT OF GENETIC TESTING

Nancy E. Weissman, ACSW, LCSW, BCD

“I think about how I would feel if I found out that the genetic pattern (that caused my child’s death) came from me. That would be hard. I’d really have to seek some real in-depth answers, if it could have been prevented somehow. It’s like killing your own kid. That’s how it would feel to me. I’d get myself fixed, then adopt if I could…”

These poignant words were spoken to us by a young father participating in a research study being conducted by the Clinical Genetics Branch of the National Cancer Institute. This father was worried that he might have transmitted a genetic mutation to his child, because his brother had died of a similar disease. “My Dad lost his first child, and I lost my first child,” he said. “It’s a round-robin.”

His heartfelt comments illustrate that learning about our genetic makeup is to learn both about our past and possible future. It opens a private window into the genetic makeup of our parents, grandparents, brothers, and sisters, and hints at our children’s future. The impact of such knowledge is heightened by the fact that our genetic makeup is both immutable and central to our identity.

Although people have been aware that disease may be passed down through families for several thousand years, our understanding of genetics, and the ability to identify specific individuals within a family as being either at high or normal population risk, puts this ancient concept into a new light. Over the past 30 years, genetic testing has evolved from a focus on diagnosis of rare diseases and reproduction to an enterprise that can identify healthy individuals at increased risk of common diseases such as cancer, psychiatric disorders, and heart disease.

Social workers provide services to an increasing number of clients who have the option of acquiring this potentially life-altering knowledge about themselves and their family members. Almost 30 years ago, Schild (1977) wrote, “The generic utility of social work practice skills and knowledge applies to this field of practice as to any other…” This

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article offers a brief look at the psychological impact of genetic testing, and illustrates social workers’ critical role in assisting individuals and families who need support with the issues and consequences of genetic testing.

Genetic disorders vary greatly. Rolland (1994) has described characteristics that define a psychosocial typology of illness. These include whether the onset is at birth, gradual, or acute; the course is progressive, constant, or relapsing; the outcome is fatal, nonfatal, or with a shortened lifespan; and the amount of incapacitation it causes (if any). Common to all is their degree of uncertainty and unpredictability. This model can be applied to genetic disorders as well.

Reducing uncertainty about the threat of disease is thought to be the primary reason that people pursue genetic testing (Wang, Gonzalez, & Merajver, 2004). A genetic test may provide information about the genetic cause of a disease that has already been diagnosed, or may inform a healthy individual about a predisposition to disease. However, genetic tests vary in the degree of certainty they can provide. For instance, the test for Huntington’s disease, a progressive, neurological condition, predicts disease with 100 percent accuracy in mutation carriers before symptoms appear. In contrast, only 40 to 85 percent of carriers of mutations in BRCA1 or BRCA2 develop breast cancer. Often, as in cystic fibrosis, discovering a disease-associated mutation provides no information regarding whether the disorder will be mild or severe.

Uncertainty also surrounds prevention and treatment issues. Is there a benefit to knowing that one is at increased genetic risk of a disease, if there is no proof that the available interventions are beneficial, or if their use is associated with anxiety or stress? Screening for a particular cancer may be associated with fear that cancer will be detected, or with the need for additional diagnostic procedures for what prove to be false-positive screening test results.

More drastic measures may require weighing the risk of the disorder against possible medication side effects or preventive surgery. For example, preventive breast removal among women who are genetically predisposed to breast cancer appears to reduce cancer risk by about 90 percent. But most women are not interested in breast removal prior to the onset of disease (Burke, 2004). One woman in our clinic, who is at high risk of breast cancer, said, “When reality is in your face about the gene, and the possibility of getting cancer or dying, it’s different than thinking you have a high risk, but not really knowing. But I don’t want to have my breasts removed. My appearance is who I am…” On the other hand, for a woman who has already been diagnosed with breast cancer, a genetic test result may help in formulating a decision regarding surgery, both to treat the cancer and to lower the risk of subsequent breast cancer (Schwartz, Lerman, Brogan, Peshkin, Halbert, DeMarco, et al., 2004).

Thus, some uncertainty may be resolved through genetic testing (e.g., a woman who does not carry her family’s BRCA1 mutation is not at increased genetic risk, nor are her children). Other concerns may not be resolved, however, because of limitations of the testing itself, or because there are doubts about the effectiveness of prevention strategies or treatments. Many people choose not to be tested, or to not know the results of a genetic test. In Huntington’s disease, for instance, only a fraction of those individuals at risk have elected to have genetic testing. To maintain normalcy and sustain hope, individuals may
prefer uncertainty to the surety of death from this degenerative disease. Individual and family values, cultural norms, and fears of discrimination and stigmatization are additional factors that influence reactions to genetic testing.

When people do choose genetic testing, how do they react to test results indicating that they have a disease-associated mutation? Largely, they respond as they would to receiving any news that is, by its nature, bad. Each person brings his or her own inventory of defenses and coping mechanisms, psychological resources, and previous experiences to the situation. The individual’s age, developmental phase, and the nature and extent of family, social, and spiritual resources are of major importance. In addition, the specifics of the medical situation, and the medical, financial, and other resources that are available, play a vital role in moderating an individual’s response.

Reactions may include shock and disbelief, anxiety, denial, and an increased sense of vulnerability. The individual may feel that life is out of control and, ultimately, may experience an existential crisis about life’s meaning. Depression due to feelings of loss, or in anticipation of losses to come, may occur, along with feelings of guilt and shame. Some people become angry, and may displace their anger onto other people or direct it inwardly (Weil, 2000). Eventually, as they do with other major life transitions, most people develop coping mechanisms that allow them to navigate the crisis successfully. Thus, people who have been tested often report a sense of empowerment and improved mood after resolving the ambiguity regarding their risk.

Parents who learn that they do not carry their family’s disease-causing mutation experience relief at knowing that their own cancer risk is not elevated, and also that their children do not share the family’s cancer predisposition and can be spared intensive screening and cancer-related worries. In our research clinic, many women who have had genetic testing for breast cancer report believing that “knowledge is power;” testing has given them a sense of control over their lives and bodies, as well as useful information for their children.

However, there is a subset of individuals who are emotionally distressed prior to testing, who also are expected to be distressed following testing (Broadstock, Michie, & Marteau, 2000). “More subtle effects caused by genetic testing - anxiety, cancer related worries, family stresses… have been reported among individuals who have tested positive” (Lerman, Shields, 2004). Decisions regarding marriage, child bearing, and careers may also be affected.

The results of a genetic test may come as a surprise, as when testing is performed during pregnancy. Or the test may confirm what has been suspected for many years. One woman at high risk of breast cancer explained, “As I get older I have this feeling… a ticking time bomb. Something is lurking in there, waiting to come out.” Others, accustomed to sharing lifelong cancer worries with other high-risk family members, find it difficult to believe that their tests are negative. Such individuals may feel guilty, different from, or isolated by their affected siblings.

Genetic testing involves both the individual and her or his family. The structure of that family, its developmental phase, communication patterns, and extent of social support will all have an effect on how an individual copes with a genetic diagnosis (Weil, 2000). Some families ascribe a meaning to a disease, which may
impart feelings of guilt or shame; alternatively, the experience may help members identify and connect with one another.

Genetic testing may arouse feelings among an individual’s relatives. Some family members may express anxiety or sadness, while others cannot acknowledge the risk that is inherent in a positive test result. An adult patient with an inherited syndrome that predisposes him to cancer regretted his parents’ refusal to acknowledge his risk of premature death, which denied him much-needed emotional support. Denial may be a defense against overwhelming emotions. Some parents feel responsible for passing the genetic trait to their children, even though it was not an intentional act (Weiss, 1981).

Some family members communicate openly, while others try to shield one another from bad news. Secrets can create problems in a family with a genetic disorder. One individual informed his family that he did not have the family’s mutation when, in fact, he did. In an effort to “protect” them, he created a chain of miscommunications, not only about himself but also about the risk of cancer to his children, who will need the correct information to make their own medical decisions.

A set of parents in our clinic did not inform their children of the results of testing they had undergone (previously, in a different laboratory), fearing that the news would be too upsetting for them. Experience has taught us that children often think about whether or not they carry a genetic mutation known to exist in their families. They pick up nonverbal cues and bits of conversation that are prone to misinterpretation; lowered self-esteem and self-blame may follow, if their thoughts cannot be clarified. We suggested that the parents share their testing results in a matter-of-fact way with each child separately. “I’m very glad we did. I’m sure I would have somehow let it slip,” the mother told us afterwards, expressing her relief.

There have been no large population studies that help us predict how people will react to the increasing trend toward testing. However, there have been smaller studies of special research populations, which, along with anecdotal evidence and experience, offer us some limited insight. One consistent finding: More people express an interest in taking a genetic test than actually take the test when it becomes available.

The decision to pursue genetic testing should be private and free from coercion. Social workers can play a critical role in helping individuals make informed decisions, by understanding the implications of testing to themselves and their families. We can identify people who are at risk of distress, and can provide crisis intervention and supportive individual, couple, or family counseling. We can teach problem-solving strategies, and help in family communication. Furthermore, we can provide referrals to support networks. Social workers are now working side-by-side with other genetics professionals to provide the counseling that is so vital for a successful outcome in genetic testing.

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**ALZHEIMER’S DISEASE AND GENETICS**

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Alzheimer’s disease (AD) affects an estimated four million Americans and presents a significant health problem due to its enormous impact on individuals, families, the health care system, and society as a whole. It affects all facets of a person’s life. Initially, the disease interferes with work and leisure activities, but eventually affects social interactions and physical health. The direct and indirect costs to society of caring for persons with Alzheimer’s disease are believed to be as much as $100 billion each year (National Institute on Aging, 2001). The human toll on those with the disease, their families, and their social support networks is immeasurable.

Scientific research now exists to help clarify the role of genetics in Alzheimer’s disease and to highlight the complex nature of this devastating disorder. According to the National Institute on Aging (2001), major breakthroughs have occurred in identifying the genetic mutations responsible for early onset Alzheimer’s disease and the genetic influences that may be risk factors for late onset Alzheimer’s disease. Research on how genetics influences Alzheimer’s disease is still in its early stage, but new understandings of the causes and risk factors for AD are beginning to draw the roadmap for the possibility of delaying the onset of the disease, and for discovering avenues for prevention.

Social work can play a pivotal role in helping those with AD, and their families, become more aware of the genetic and psychosocial implications associated with the disease. As more is uncovered about the science of genetics, there exists greater promise for enhanced health and well-being of those with Alzheimer’s disease, and greater opportunities for social workers to make major contributions within this emerging area of practice (National Association of Social Workers [NASW], 2003a).
About Alzheimer’s Disease

Alzheimer’s disease is the most common form of dementia among people 65 and older. The term dementia is used to describe a syndrome in which progressive deterioration in intellectual abilities is so severe that it interferes with a person’s usual social and occupational functioning. The disease progresses in stages over months or years, and gradually destroys memory, reason, judgment, language, and, eventually, the ability to perform even the simplest of tasks.

As a person gets older, normal changes occur in all parts of the body, including the brain. Some people develop problems with memory and cognition, but this does not necessarily mean that an individual has—or will develop—Alzheimer’s disease. Although AD is not considered a normal part of aging, about three percent of men and women aged 65 to 74 have the disease, and nearly half of those aged 85 and older may have the disease (Alzheimer’s Association, 2003).

The Genetic Risks Associated with Alzheimer’s Disease

There are two basic types of Alzheimer’s disease: familial and sporadic. Familial Alzheimer’s disease is a rare form, affecting less than ten percent of all AD patients. Familial Alzheimer’s disease has an early onset, meaning the disease develops before age 65. In cases with a familial link, the genetic defects may result in people developing the disease as young as 30 to 40 years of age. Research has shown that, among people with a strong family history of early onset Alzheimer’s disease, 50 percent of cases were caused by a genetic defect (NIA, 2003).

The majority of AD cases are sporadic, meaning that they have no known cause. Because this type of AD usually develops after age 65, it is often referred to as “late onset Alzheimer’s disease.” Late onset AD—which shows no obvious inheritance patterns—is the most common form of the disease, accounting for 90–95 percent of all cases. However, in some families, clusters of cases have been seen. A specific gene has not been identified as the cause of sporadic AD, but genetics does appear to play a role.

Researchers have identified an increased risk of developing late onset AD, related to the apolipoprotein E (ApoE) gene found on Chromosome 19. This gene comes in several different forms (alleles), but the three that occur most frequently are: ApoE2 (E2), ApoE3 (E3), and ApoE4 (E4). Individuals inherit one apoE from each parent. Having one or two copies of the E4 allele increases a person’s risk for getting the disease, but does not mean onset of AD is certain (NIA, 2003).

Implications

Individuals considering genetic testing could greatly benefit from expert counseling to help them understand the implications of testing, to understand the results accurately, and to deal with the psychosocial consequences that may arise as a result (Oktay, 1998). Social workers involved in genetic counseling can assess social service needs, make referrals, and provide case management and crisis intervention services (Rauch, 1988).

Since Alzheimer’s disease may be accompanied by many unforeseen problems—including financial difficulties, issues of capacity, and decisions about long-term care—families and individuals often need professional guidance to help adjust to the challenges that may arise over the course of the disease.
Social workers have a professional and ethical responsibility to become aware of the implications associated with a genetic diagnosis, genetic testing, and genetic research, in order to assist individuals and families, influence the quality of service delivery, and shape public policy as it relates to genetics (NASW, 2003a). In the shadows of the field of genomics is a concern for how society will handle the information obtained from genetic research and testing (Freedman, 1998; Neilson, 1999). Therefore, it is imperative that social work take an active role in ensuring that clients are protected against genetic discrimination in areas including access to care, health and life insurance, employment, housing, and adoption (NASW, 2003b).

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Resource
Alzheimer’s Disease Education and Referral Center (ADEAR), www.alzheimers.org/adear. This Web site has current, comprehensive information on Alzheimer’s disease (AD) and resources from the U.S. Government’s National Institute on Aging (NIA).

GENETIC TESTING: AN ETHICAL DOUBLE-EDGED SWORD
Phyllis N. Black, DSW, ACSW, LSW

Introduction
The last decade has witnessed a revolutionary explosion of knowledge in human genetics, which has had profound implications for all fields of social work practice. At the core of the explosion is the Human Genome Project, which provides access to further understanding of the molecular essence for numerous diseases and disorders. The more than 4,000 diseases with a genetic predisposition include: Tay Sachs, sickle cell anemia, cystic fibrosis, fragile X (a leading cause of mental retardation), Huntington’s disease, diabetes, heart disease, Alzheimer’s disease, some forms of cancer, and mental illness (Collins, 2003). The discovery of disease-related genes has spawned the technology
for genetic testing to detect chromosomal abnormalities, which may indicate or “red flag” disease entities.

**Ethical Challenges of Genetic Testing**

Attention to ethical issues related to genetic testing has not kept pace with the dramatic biotechnological developments. While significant government funding was set aside to attend to the ethical, legal, and social implications (ELSI) of the Human Genome Project Information, little progress has been made in addressing the thorny matrix of moral perplexities that have mushroomed (Ramsay, 2001). The promise of genetic testing, which holds out the possibility of enhanced health and well-being, is tempered by serious concerns for individuals, their families, and for society as a whole (Freedman, 1998; Human Genome Project Information, 2004a). A risk-benefit paradigm, articulating the relative advantages versus the limitations of testing is a reasonable approach to visualizing the salient ethical challenges (Beauchamp & Childress, 2001).

**Benefits of Testing: Knowledge is Power**

Data derived from testing inform medical and social decisions. Most profoundly, screening has the potential for improving the quality of lives. Testing can facilitate reasoned choices concerning family planning, and can minimize the potential for bearing offspring with devastating disorders (Watson, 2000). For individuals in whom an etiological genetic diagnosis has been established, treatment, preventive life-style measures, or customized surveillance (such as mammograms or colonoscopies) may be undertaken (Human Genome Project Information, 2004b). Illustrations include familial adenomatous polyposis, breast/ovarian cancer, and PKU.

For genetically based developmental disabilities, such as fragile X and Smith-Magenis syndromes, testing can pinpoint the underlying etiology and direct management to modifying the environment to maximize individual potential (Finucane, 1996). Furthermore, a confirmed diagnosis may entitle clients to a panel of services tailored to their needs. In the realm of psychological advantages, persons with high-risk family backgrounds (i.e., Huntington’s disease, cystic fibrosis, cancer) may live in dread for themselves and their children. A negative test result can alleviate the angst of uncertainty and provide a sense of relief. (Schindler, Kerigan, & Kelly, 2004; Access Excellence Resource Center, 2004). Finally, genetic testing paves the way for the development of gene therapies for treating diseases previously deemed incurable.

**Limitations of Testing: The Downside**

The advantages of genetic testing must be balanced against a backdrop of current and potential pitfalls. A commanding limitation relates to the present disparity, a “therapeutic gap” between a genetic diagnosis and the availability of treatment; “genetic prophecy” outstrips current disease management (Smith, 2002). For example, Huntington’s disease is predictable by genetic testing, yet there is currently no available treatment. It may be morally defensible to burden a potentially afflicted individual with the diagnosis of a devastating disease in advance of its possible onset. How can this be reconciled with the injunction of beneficence—the primacy of the best interest of the client, or the sacrosanct nolo nocere proscription, “Do no harm?”

The risk of genetic discrimination also looms as a toxic byproduct of testing. Diagnosis of a genetic condition or susceptibility may socially stigmatize the individual, who may
also be further victimized by discrimination in employment, life and health insurance, home mortgages, pensions, and loans (Human Genome Project Information 2004a).

While there exists a mosaic of federal and state privacy laws, in their present formulation they fail to adequately protect the confidentiality of an individual’s genetic information (Human Genome Project Information, 2004a). This lack of privacy not only marginalizes genetically affected persons, but also serves as a deterrent to those considering testing. The financial burden of testing (hundreds to thousands of dollars), generally not covered by insurance, raises an issue of distributive justice (Human Genome Project Information, 2004a). As a matter of social policy, should access to testing be based on income?

Current testing technology is not foolproof; false negatives and positives can occur, and wreak havoc on life decisions and psychological well-being. Furthermore, the probabilistic, rather than definitive nature, of some tests leaves individuals in a limbo of uncertainty. A test confirming a genetic disorder can trigger psychological trauma; paradoxically, a negative result may also cause psychological despair (e.g., survivor’s guilt, depression) (Schindler, Kerrigan & Kelly, 2004). By virtue of the genealogical nature of inherited traits, test results of one family member can reverberate throughout the entire family, and can create emotional and interpersonal stress (Access Excellence Resource Center, 2004).

A further drawback of testing is the possibility that inadvertent genetic information, such as paternity issues or predisposition to diseases not under consideration, may be revealed. The prospect of excessive use of testing with the provision of more information than can be effectively processed is troublesome. For example, prenatal genetic testing is becoming routine. Prospective parents are inundated with a plethora of statistical probabilities regarding their offspring, which touches on the principle of self-determination: Does the patient have a right not to know? The issue of mandatory screening is fraught with ethical perplexity, and undermines the imperative of informed consent and individual free will. There is precedent for universal testing (currently, for example, PKU testing in newborns is mandated by law). Could other tests be added to the required roster, raising the specter of a slippery slope to eugenic controls, whereby the government would determine what constitutes appropriate characteristics for our populace?

Conclusion

This risk/benefit overview suggests that genetic testing is a double-edged sword with compelling advantages and disadvantages. At this early stage in the evolution of genetic testing, it would be prudent to adopt a cautious, judicious approach that maximizes benefits while minimizing pitfalls. Social workers, with their holistic and ecological perspectives, have much to bring to this complex table of opportunity and challenge (Taylor-Brown & Johnson, 1998; NASW, 2003). Clients will benefit from direct social work interventions that help them make informed decisions about testing, and to cope with the psychosocial sequelae of testing results. On the macro level, social workers can also bring their longstanding commitment to privacy, self-determination, diversity, and distributive justice to participate in the crafting of public policies that are humane, egalitarian, and responsive to individual and societal well-being.

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GENETICS AND GENETIC TESTING: POLICY IMPLICATIONS

Mickey J.W. Smith, ACSW

According to the NASW Standards for Integrating Genetics in Social Work Practice, social workers are often the first to provide psychosocial services to individuals and families with genetic disorders; the profession has long recognized the importance of understanding genetics in delivering services (NASW, 2003). The Human Genome Education Model (HUGEM) project, funded by the National Institutes of Health, was co-chaired by two social workers, and NASW was an active participant. Two social workers were also on the steering committee of the National Coalition of Health Professionals in Genetic Education (NCHPGE), which has developed core competencies in genetics for all health care professionals. Since the success of the National Human Genome Research Institute (NHGRI) in sequencing the three billion DNA letters in the human genome, much attention has been given to the role of genetics in delivery of services, policies affecting health care and its delivery, employment, and other related matters. The purpose of this article is to provide a brief overview of genetics within the health care system, discuss relevant policy issues, and present key recommendations for consideration by the social work profession.

The Impact of Genetics
Genetic testing in the health care field has evolved, and the use of such procedures to identify, and potentially treat, a variety of

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diseases has increased over the past decade. Such growth has not been limited to chronic medical conditions (e.g., cystic fibrosis, Alzheimer’s disease), but is expanding in research and potential use in treating chronic behavioral health conditions (e.g., schizophrenia, alcoholism). In fact, research on the genetics of mental illness that identified the genes that increase an individual’s risk of developing schizophrenia, depression, and bipolar disorder was named the No. 2 scientific breakthrough of 2003 by Science magazine. Furthermore, research supported by the National Institute on Drug Abuse has demonstrated that substances of abuse (e.g., cocaine, ecstasy) each have unique genetic markers that affect the brain differently.

Relevant Policy Issues
Policy issues relevant to genetics and genetic testing are diverse, ranging from performing genetic tests on individuals for identification of potential risk for genetic disorders to the impact of such test results on employment and health insurance, as well as protections of genetic test results used in research studies. These issues cross the private and public sectors of health care and other settings, and are affected by both state and federal legislation. The benefits of identifying risks for certain genetic disorders could result in useful prevention, early treatment, or care planning and management of genetic disorders. However, this genetic information could be used in a manner that would result in negative consequences for a large number of people.

Multiple studies indicate that one of the major concerns expressed by people associated with genetic testing is the fear that results will be used to deny jobs or health insurance to individuals (NGHRI, 2004a). In documented cases, carriers or those at risk of certain genetic disorders hid information from employers. In other cases, individuals were fired after genetic risks were indicated as the result of testing. Individuals have also been denied health insurance based on genetic test results or a family history of certain genetic disorders. Other individuals have been counseled to purchase life insurance prior to a genetic test so as to ensure that it would not be denied if the results were positive.

In February 2000, President Clinton signed Executive Order 13145 to prohibit discrimination in federal employment based on genetic information, which prevents federal government agencies from obtaining genetic information from employees or job applicants and from using such information in hiring and promotion decisions. The U.S. Senate passed the Genetic Information Nondiscrimination Act of 2003 (S.1053) by a vote of 95 to 0; however, it has not been voted on by the U.S. House of Representatives. The bill would prevent health insurers and employers from using genetic information to determine eligibility, set premiums, or hire and fire people. Although 40 states have similar laws to S.1053, no federal law currently protects against such discrimination.

No laws expressly protect genetic information collected in research studies, although it is assumed that existing human protections procedures used in such studies would apply. While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides for certain protections of medical information and the use of such information in research studies, many gaps remain that do not protect individuals in a comprehensive manner (NGHRI, 2004b). In fact, HIPAA allows for the use of medical information collected by providers for research purposes within a set of certain circumstances. However, this law does not define protections of research data (e.g., genetic test
results) being provided to clinical staff that may or may not be affiliated with the research.

**Implications for Social Workers**

The social work profession has a long history working to shape public policy that protects the interest of consumers/clients, and advocating for adequate and appropriate health care services for people. There is a clear need for continuing advocacy on behalf of the clients served by social workers and participation in the creation and passage of comprehensive legislation protecting individuals from the various forms of discrimination based on the results of genetic tests. These efforts—advocacy for clients and their legal protections—must occur at local, state, and federal levels.

An executive order prohibits federal government agencies from using genetic information in a discriminatory manner; however, these protections are not afforded to everyone in the United States. Although 40 states have laws that provide some form of such protections, the laws are inconsistent. The need for federal legislation to protect all citizens from genetics-based discrimination is apparent, and the need to ensure such protections will continue to grow as the field of genetics research grows. As previously discussed, opportunities exist for social workers to advocate for the passage of such legislation in the form of S.1053. Furthermore, 10 states do not have similar laws intact to protect individuals from such discrimination—resulting in the need for advocacy at the state level as well. The role of advocacy by social workers in the field of genetics is expressly defined in the *NASW Standards for Integrating Genetics in Social Work Practice* (See Standard 9), which discusses the need to advocate on behalf of clients to ensure fair social policies and access to quality genetic services (NASW, 2003).

Social workers also have a rich history in the shaping of organizational policy as it relates to genetics and service delivery. Such efforts should continue, particularly within agencies where genetic testing is used as a part of either research or the provision of services. Social workers can be more involved in creating human protections standards through involvement of institutional review boards for research studies. Understanding genetics and genetic testing will help prepare the profession for the challenges ahead.

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RESOURCES AND REFERRALS IN GENETICS FOR SOCIAL WORK PRACTITIONERS

Virginia Lapham, PhD, MSW, MEd

Social work has included the concept of heredity and its influence on individuals and families since its inception. During the past four decades, social work pioneers have provided leadership in advocating the inclusion of genetic information into practice. It is now recognized that understanding the science of genetics is essential for all social work practitioners.

Genetic resources have increased rapidly during the past decade, following the explosion of genetic information associated with the Human Genome Project. The intent of this article is to provide a review of selected references and resources in genetics for social work practitioners, and to include information on genetic services for clients. Since the field of genetics is rapidly changing with the continuous discovery of genes associated with medical conditions and/or behavioral characteristics, an emphasis is placed on electronic resources that can be rapidly updated.

GENETIC SOCIAL WORK RESOURCES FROM NASW

NASW maintains a commitment to establishing the social work profession as a leader in the field of genetics (NASW, 2003a). In its policy statement, Genetics, NASW urges social workers to educate themselves through formal and informal educational opportunities about current issues in genetics, to discuss the potential for genetic discrimination, and to take a stand on supporting or opposing current policy issues on genetics.

NASW Standards for Integrating Genetics in Social Work Practice (2003b): Social workers are often the first persons to provide psychosocial services to individuals and families with genetic disorders. It is essential that social workers stay abreast of the ethical, legal, and psychosocial implications of genetic diagnoses, testing, and research (NASW, 2003b). The NASW Standards for Integrating Genetics in Social Work Practice is an important resource for all social work practitioners.

An NASW practice update titled Social Work’s Role in Genetic Services provides clinical guidance for social work practice in genetics (Taylor-Brown & Johnson, 1998). These and other genetics resources are available to members on the NASW Web site (www.socialworkers.org).

Additionally, course work in the biological sciences is now recommended by the Council on Social Work Education (CSWE) as a prerequisite for students entering graduate social work programs across the country; professional schools of social work are increasingly including classes and courses in human genetics. For more information, visit www.cswe.org

PROFESSIONAL GENETICS ORGANIZATIONS

Clients with genetic conditions may wish to receive referrals to medical geneticists or genetic counselors. Medical geneticists are MDs, PhDs, or MD-PhDs with specialized training in the diagnosis of genetic disorders. Genetic counselors are certified by the American Board of Genetic Counselors; they provide evaluations and counseling related to genetic issues. The goal of genetic counseling is to provide accurate information about diagnoses, risks to family members, and medical referrals.

American College of Medical Genetics (www.acmg.net/): This Web site provides information
on ordering educational materials, such as a CD-Rom on genetics in clinical practice, “Team Approach,” developed by Dartmouth Medical School and the Centers for Disease Control, and Prevention and a member directory of medical geneticists.

**National Society of Genetic Counselors (NSGC)** (www.abgc.net/genetics/abgc/abgc-menu.shtml): NSGC provides guidelines regarding when to refer clients for genetic counseling. The Web site also provides a user-friendly search engine to help locate genetic counselors in cities and states across the country.

**OTHER PROFESSIONAL ORGANIZATIONS**

Genetic issues impact all professionals in health care settings; professional associations and organizations with multiple disciplines are developing genetic resources applicable to social workers.

**National Coalition of Health Professional Education in Genetics (NCHPEG)** (www.nchpeg.org): The NCHPEG Web site includes genetics standards for health professionals, guidelines for taking family histories, and links to other genetics resources.

**American Occupational Therapy Association (AOTA)** (www.aota.org): AOTA offers an online course in genetics for occupational therapists that is adaptable to social work practice. The course includes genetic inheritance; ethical, legal, and social issues arising from advances in genetic research; and the role of the practitioner with individuals and families with genetically linked disorders.

**American Psychological Association (APA)** established a work group on genetics research that now has its own Web site, with resources that include educational opportunities, ethical issues, funding sources, and cognate organizations of genetics professionals. For more information, visit www.apa.org/science/genetics/homepage.html

**UNIVERSITIES AND MEDICAL CENTERS**

Genetics professionals working in academic settings are excellent sources of referral for practitioners and clients with genetic concerns. These genetics professionals often offer classes on basic genetics, and some speak at local meetings of health professionals and/or consumers. A few university and medical center resources are identified below.

**The Genetics Education Center, University of Kansas Medical Center** (www.kumc.edu/gec/): This site includes information on genetic conditions, support groups, genetic societies, clinical resources, genetics education, genetic computer resources, advocacy, and glossaries.

**Howard University Medical Center, National Human Genome Center** (www.genomecenter.howard.edu/intro.htm): This Center was established to bring multicultural perspectives and resources to an understanding of human genome variation and its implication for disease prevention and health promotion. Its genetics programs relate to diseases common in African American and other African diaspora populations.

**GOVERNMENT RESOURCES**

Since the onset of the Human Genome Project in 1990, two government agencies—the National Human Genome Research Institute and the Department of Energy—have been funded to carry out scientific research and to simultaneously utilize up to five percent of the Project’s
budget on the ethical, legal, and social issues being raised and on education.

**National Human Genome Research Institute (NHGRI)** (www.nhgri.nih.gov/) is the branch of the National Institutes of Health (NIH) funded to conduct research and create education opportunities. Educational resources on its Web site include genetics education modules, fact sheets on issues including genetic discrimination, guidelines for presentations on genetics, and speakers on genetics topics for both professionals and the public.

**Department of Energy (DOE)** was also funded to conduct genetic research and create education opportunities. Visit www.ornl.gov/sci/techresources/Human_Genome/elsi/behavior.shtml

Additionally, the National Library of Medicine’s Genetics Home Reference Web site (http://ghr.nlm.nih.gov) is an excellent resource for information and articles on genetics. There is also a list of resources for health professionals.

**CONSUMER ORGANIZATIONS**

Consumer groups started by persons who are affected by genetic conditions, or whose family members are affected by genetic conditions, often employ personal experiences as a major part of their resources. They may include support groups and publications developed by consumers. Information about these groups may be helpful to clients diagnosed with genetic disorders.

**National Organization for Rare Disorders (NORD)** (www.rarediseases.org) is a federation of voluntary health organizations dedicated to helping people with rare diseases and assisting the organizations that serve them.

**Genetic Alliance** (www.geneticalliance.org) is an umbrella organization that includes genetic support groups. The Alliance Web site provides information on genetic conditions and links to many specific disease Web sites. It also holds annual educational meetings, is involved in advocacy and policy issues at the national level, and provides speakers on consumer issues, publications, and brochures.

**National Alliance for the Mentally Ill (NAMI)** (www.nami.org/) is a support and advocacy organization of consumers, families, and friends of people with severe mental illnesses. NAMI is not a genetics organization per se, but rather monitors and provides information to members about research in genetics and mental illnesses. The NAMI Web site includes a help line.

**OTHER ORGANIZATIONS**

The March of Dimes (http://www.modimes.org/): This organization is committed to improving the health of babies by preventing birth defects and infant mortality. They have developed a series titled “Genetics and Your Practice,” to help professionals integrate genetics into patient care. This resource can be downloaded from their Web site.

Social workers are advised to return to these recommended sites periodically to check for the latest information. Our knowledge about the associations between human genes and human development will continue to evolve well into the foreseeable future, and social workers will play a central role in delivery of bio-psychosocial services to clients with genetic issues.

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and educate consumers and health professionals on the Human Genome Project and its ethical, legal, and social issues. She currently does genealogical and genetic family research and writing. Dr. Lapham can be contacted at vlapham@cox.net

References


chromosomal abnormalities. However, with the completion of the human genome sequence, it has been found that every disease has some genetic component. Our clients are responding to increased public coverage of genetics by asking questions and expressing their concerns, often about information gained from the media or the Internet. More and more, common diseases, including heart disease, diabetes, cancer, Alzheimer’s disease, depression, schizophrenia, autism, and learning disorders have been found to have a genetic component.

Scientists have discovered that everyone has several glitches in his or her genes that could cause problems under specific circumstances. Some are more susceptible to genetic conditions than others, but everyone has at least ten altered genes that could put them at risk for a genetic condition. With predictive genetic testing becoming available for common diseases (such as cancer and diabetes), an increasing number of healthy individuals will seek counseling to sort out possible ramifications for themselves and their family members.

It is also crucial that social workers are aware of the impact of the new genetics advances on reproductive choices, the controversy about stem cell research, and the importance of continuing animal genetic research. We must be cognizant of diversity and normalcy issues. In doing so, it is critical that social workers be mindful about the fears of those who are coping successfully with genetic conditions (e.g., dwarfism and hereditary deafness), that future generations with the same genetic conditions will be gradually eliminated by new reproductive choices. In the future, social workers will gain more knowledge about hereditary mental illness and behavioral disorders, and must be in a position to evaluate, once again, the influences of nature and nurture.
What basic genetic facts are important for social workers to know?

Genetic disorders can pose major health problems. Approximately 40 percent of infant mortality and 30 percent of pediatric hospital admissions are attributed to genetic diseases. Many adult diseases, including cardiovascular disorders, some cancers, diabetes, and Alzheimer’s disease have genetic determinants. Evidence also suggests that schizophrenia and mood disorders can be inherited (McGuffin & Murray, 1991).

“Medical genetics” is the discipline that applies genetics to clinical practice. It is comprised of the diagnosis and treatment of genetic disorders, study of inheritance of diseases in families, provision of genetic counseling to families, identification of genes that cause diseases, and mapping (finding the exact location of a gene on a chromosome) and sequencing those genes.

Genes are tiny units of inheritance, located in the nucleus of every cell in our body, which contain our DNA, a long thread-like molecule that carries all of our genetic information. Genes are strung together like beads on the 23 pairs of chromosomes we inherit from each of our parents, which total 46 chromosomes. The four basic subunits of DNA contain the bases adenine (A), guanine (G), cytosine (C), and thymine (T). If we printed these letters, which are contained in the three billion bases of DNA within the entire human genome in a standard print size, we would have a stack of paper about as tall as the Washington Monument (National Human Genome Research Institute, 2003).

The Human Genome Project, which mapped and sequenced the entire genetic material of human beings, estimates that each of us has approximately 30,000 genes in our body. Of everyone’s genetic makeup, 99.9 percent is the same. Some genes, however, have different forms; it is these variations that contribute to the wonderful diversity of the human family (Eanet and Rauch, 2000).

There are three types of genetic disorders: single gene (either autosomal dominant, autosomal recessive, or sex-linked), chromosomal, and multifactorial disorders. Altered genes cause single gene disorders, an error in a single unit of genetic information. Examples of single gene disorders are sickle cell disease, neurofibromatosis, fragile X syndrome, achondroplasia dwarfism, muscular dystrophy, and certain forms of breast and colon cancer.

Chromosome disorders are caused by an excess or deficiency of a chromosome segment or entire chromosome. Chromosome disorders are characterized by mental and physical retardation, unique physical features, and by an increase in the incidence of congenital (at birth) anomalies. Examples are Down syndrome, Turner syndrome, trisomy 13 and 18, and Klinefelter syndrome. Multifactorial conditions—many of them common diseases, including mental illnesses, asthma, hypertension, coronary artery diseases, cancer, diabetes, alcoholism, and the majority of birth defects—result from a combination of genetic predisposition and environmental factors. Multifactorial conditions tend to recur in families.

What are the different types of genetic tests now available to our clients, and what are their objectives?

Diagnostic laboratories now offer approximately 1,000 genetic tests. Some genetic tests look at whether or not the number of chromosomes is correct or abnormal in its arrangement (for example, detecting Down syndrome in a fetus). Other tests look at the actual DNA sequence
of a particular gene. Genetic tests can be done to confirm a diagnosis, to detect a carrier state in unaffected individuals who have or plan to have children, to predict future illness, and to evaluate one’s response to drug therapy. Prenatal testing is available through amniocentesis, chorionic villi sampling (CVS), or pre-implantation genetic diagnosis of an individual embryo before implantation. Newborns are tested for several genetic disorders such as phenylketonuria (PKU) that require immediate treatment. Children can be tested to confirm a diagnosis, but unless intervention is available, predicting adult-onset disorders is generally discouraged. Although the number of genetic tests is increasing, most only apply to families in which there is a strong history of a genetic disorder. For example, genetic tests for BRCA1 and BRCA2 (two susceptibility genes for familial breast-ovarian cancer) are usually only offered to women with a strong family history of breast and/or ovarian cancer. However, it is predicted that in the near future, tests that predict disease susceptibility will be offered to anyone who is interested, regardless of family history.

It is important to recognize that most genetic tests developed in the future for common diseases like heart disease, Alzheimer’s disease, cancer, diabetes and mental illness will not be diagnostic, yielding a “yes” or “no” answer. They will only predict relative risk figures. Scientists hope that predictive genetic information will not be misused in a discriminatory way in such areas as employment opportunities and health insurance (Collins, 2003).

**What benefits and risks associated with new genetic technology, genetic testing, and research will social workers need to be familiar with?**

Potential benefits derived from the results of new genetic technology are tremendous. New light is being shed already on specific genetic disorders. New treatments are being developed and made available for those affected with genetic disorders. Information is being gleaned about human development and gene function. But along with these real benefits come potential risks. Although the decoding of the human genome will eventually lead to many positive developments, such as prevention of and treatments for disease and the development of drugs adapted to individual needs, it may also impinge upon medical privacy and the insurability of people born with genetic predispositions to certain illnesses.

There is also the risk of using genetic knowledge to create designer children with superior intelligence and looks. As the Human Genome Project helps unravel our biologic determinants and as predictive testing becomes more commonplace for common diseases, fears about genetic stigmatization and labeling are on the rise. Individuals have reported that they have been excluded from insurance or jobs because they are at risk for genetic disorders, even though they are in perfect health. Individuals and families faced with societal stigmatization because of genetic disease or carrier status need our assistance. Issues of discrimination, privacy,
and confidentiality are familiar to social workers in meeting the multi-dimensional societal and family needs of clients.

Individuals are becoming increasingly concerned, not only about protecting future generations from diseases, but also about protecting themselves and their children from potential exclusion from health care, employment, and educational opportunities. There exists a possibility for misuse of genetic information by insurance companies, employers, schools, adoption agencies, and the government. If we are known not to have perfect genes, will we still be acceptable to society? Will privacy of our genetic information be respected in this age of computerization and managed care? Will our genetic information be shared with other family members who will be implicated, but who may not want to know? It is essential that, as social workers, we respect genetic diversity and fend off those who do not respect the uniqueness of the individual, regardless of his or her genetic makeup.

Joan O. Weiss, ACSW, LICSW, was the founding director of Genetic Alliance, a national support, education, and advocacy organization for persons living with genetic conditions. She currently serves as the vice-chair of the NASW Foundation Board of Directors and was a member of the NASW Standards for Integrating Genetics in Social Work Practice work group. Joan can be contacted at weissjns@erols.com